THE COMPONENTS OF COURAGE IN CHRONICALLY ILL ADOLESCENTS: A PHENOMENOLOGICAL STUDY

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DEDICATION

This work is dedicated to my husband, Don. It is also dedicated to my daughters, Julie, Lara, and Alisa. Finally, it is dedicated to my parents, Elvera and John Marschhausen.

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I wish to first of all thank the adolescents who participated in this study. They are truly courageous and they provided me with a great amount of inspiration and hope as I worked to gain an understanding of their experiences. I feel priviledged and grateful for the opportunity to share those experiences.

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CHAPTER 1

INTRODUCTION

Socrates: "Then, Laches, suppose we set about determining the nature of courage, and in the second place proceed to inquire how the young men may attain this quality by the help of study and pursuits. Tell me, if you can, what is courage?"

Plato

Courage has been commonly identified as an important variable in patients successfully dealing with hospitalization and illness. It is not, however, a concept that has been completely defined in the nursing or in other literature. Little and Carnevali (1976) identified lack of courage as an often overlooked diagnosis and stated that courage is an area of nursing knowledge and skill that requires more research. In addition, courage has been identified in the literature as one component of caring (Mayerhoff, 1971) and caring was seen as an essential component of nursing by Carper (1979). Others, including Leininger (1981) and Watson (1979) view caring as <u>the</u> essential component of nursing. Watson (1979) identified courage as a human strength that "accounts for remarkable coping with,

adjusting to, overcoming, or accepting one's health-illness condition (p.206).

At the same time that the importance of the concept of courage is being recognized in nursing, efforts to describe and define courage in the literature are seemingly romanticized and/or contradictory. As far back as Socrates writers seem to have taken a pessimistic view of man's ability to grasp the nature of courage and/or to provide clues to the origins or development of courage. Two recent studies in the psychological literature (Evans & White,1981; Asarian,1983) have made efforts to define courage. While Asarian's study utilized a phenomenological approach to identify the structure of courage, Evans and White utilized an experimental design and approached courage from the perspective of fear. Neither study addressed courage from the perspective of one who is experiencing illness.

One recent development in nursing which may aid in defining and describing courage from the perspective of a person experiencing illness is the recognition and acceptance of the qualitative phenomenological approach and method of research. Since phenomenology seeks to give a detailed explanation of the essence, structure or

form of human behavior and experience from the perspective of the person being studied (Valle and King, 1978), an increasing number of articles in the nursing literature propose the use of the phenomenological approach to research in nursing (Davis, 1978; Munhall, 1982; Oiler, 1982; Omery, 1983 Parse, 1981; Watson, 1979;). Munhall (1982) stated that qualitative methods, particularly in theory development may be more consistent with nursing's stated philosophical beliefs. Subjectivity, shared experience, shared language, interrelatedness, human interpretation, and reality as experienced rather than contrived are mentioned as nursing's beliefs. Additionally, the emphasis in clinical nursing practice is on observation, interview, interaction, and interpersonal relations in an attempt to understand the patient's perceptions of a situation. The phenomenological approach seems more appropriate to clinical research of this nature (Davis, 1978). The experience of courage is subjective and must be studied from the perspective of the person experiencing it (Little and Carnevali, 1979). In phenomenology the primary emphasis is on the understanding of the phenomenon as it reveals itself to the person experiencing it.

Although courageous behavior is generally admired in anyone, it is especially intriguing and awesome when displayed by children. Coles (1967) describe the courage of children involved in the crisis of the Civil Rights Movement of the 1960's. Time (1982) in a cover story special report described the courage of children of war. Courage is also an important concept when children experience chronic illness. As chronically ill children develop during adolescence, health care professionals have often been struck by the meaning and focus that some have derived for their lives; they are struck by the courage with which such individuals approach their human predicament. It is often the existential-phenomenological factors which provide such meaning and focus. (Watson, 1979).

Statement of the Problem and Purpose

The research problem of this study was: What are the common components of the lived-experience of courage in chronically ill adolescents? The purpose of the study was to identify the common elements of courage as it is experienced in chronically ill adolescents. In identifying the common elements of courage, an

essential structure of courage experienced by chronically ill adolescents was derived.

Justification of the Problem

Much has been documented in the literature on the psychosocial effects of hospitalization and medical procedures on children (Ack, 1983; King & Ziegler, 1983). While being hospitalized is a stressful and anxiety producing situation for many adults, the problem is compounded for children who have limited understanding and who are often provided with limited information regarding their condition or what is happening to them. As a result psychological, learning and behavioral disturbances are reported (Douglas,1975; Quinton and Rutter, 1976). Much has been done and written about preparation for hospitalization and procedures (ACCH Publication, 1981) in order to reduce or eliminate the adverse effects. Crocker (1981) stated, however, that many of the preparation efforts may not produce the desired outcome of reducing psychological disturbance in children and/or families. Sometimes the illness and therapeutic regimen is not a traumatic event and each case requires a different approach. Knowledge about the structure of courage

would aid health care personnel in identifying the amount and nature of preparation efforts which an individual might require.

Little and Carnevali (1976) identified three high-risk situations for lack of courage. There is a high risk of a deficit in courage when a change in body image has occurred, when an individual is required to accept pain or to inflict pain on himself or when the decision regarding infliction of pain may present a risk to the self-concept or body integrity of the individual. All of these situations occur when children have a chronic illness with the accompanying hospitalizations and procedures. Nursing has very few therapeutic interventions to help clients to deal with such a lack of courage. Indeed, we have little understanding of even the experience of courage so that the process of encouragement can occur.

Encouragement is frequently written as a non-specific intervention. Such interventions as "encourage the patient to express his feelings", "encourage the patient to follow his prescribed regimen", or, "encourage the patient to develop new health maintenance patterns" are often recommended. However, these interventions are difficult to accomplish

when the concepts of encouragement and courage are not clearly defined. Courage is an area of nursing knowledge and skill that requires more research and effort (Little and Carnevali, 1976). Once the components of courage are identified further research may be stimulated regarding the process of development of courage and interventions for the lack of courage.

The impact of such research is widespread. One population which could especially benefit from such research on courage is the adolescent population. There are numerous problems of adolescents for which "encouragement" would be helpful. Examples of problems which require encouragement to overcome include suicidal thoughts and drug abuse. Adolescents are often more affected by the interruption in the accomplishment of their developmental tasks than they are by the illness itself. Such disruptions, according to Erickson (1968), may result in ego despair rather than ego identity. When adolescents experience ego despair, it is not unreasonable to think they may also be susceptible to a lack of courage.

Courage is an especially important concept for a child or adolescent who is chronically ill and must repeatedly face hospitalizations, treatments and

procedures. Ack (1983) states that although long-range illnesses generally have continuous stressful effects on children and their families, this sitution does not need to occur when health care personnel attend to the stress factors associated with chronic illness. Such factors include: forced dependency upon medications, parents and physicians; forced passivity as treatments and procedures are conducted; anxiety about the possibility of incapacitation or death; and, poor self-concept which occurs as a result of feelings of being different. Many children facing such problems seem to develop a mastery and control of their problems which astounds adults. A study of such children may identify components of courage and also identify variables which affect the emergence of courageous behavior.

A study which is carried out utilizing a phenomenological approach can contribute to scientific methodology, concept clarification, and theory building for nursing in addition to adding to the understanding of courage in chronically ill adolescents. Many research questions proposed by nurses are not amenable to scientific investigation via quantitative methods and thus are not pursued. Norris (1982) stated that "there is increasing evidence that qualitative methods are

often the more efficient or sole manner of studying an empirical situation." (p.38) Such would seem to be the case with courage, since it is such an abstract and subjective concept.

Conceptual Orientation

Hinshaw (1979) discussed the theoretical structure appropriate for different types of investigations. She asserted that when concepts are vague and undefined, a conceptual orientation rather than a conceptual or theoretical framework is a more appropriate research structure. Such a conceptual orientation requires that the concepts be defined and their properties be described qualitatively using design structures such as phenomenology. Since phenomenology is an approach as well as a method and content (Giorgi, 1971), the approach of phenomenology provides the conceptual orientation for this study. Such an approach within its historical context and the use of the phenomenological approach in nursing is described.

The Phenomenological Approach

Historical development of phenomenology

During the nineteenth century the extraordinary advances accomplished in the natural sciences led to their acceptance as the only appropriate standard for truly scientific study. The division between quantitative methods and other ways of knowing and understanding phenomena was accomplished without questioning whether other means of knowledge besides the "scientific" might satisfy the criteria of precision and verifiability. Also, a strong reductionist attitude was adopted which affected all fields of intellectual activity. (Tymieniecka, 1962). Phenomenology emerged as an attempt to reconcile philosophy to science.

> "According to the orientaton of phenomenology, philosophy and science merge and complement one another when science is understood in the light of phenomenological principles...Phenomenological philosophy intends to provide a methodological basis for all fields of inquiry, a basis which satisfies the criteria of precision and verifiability and which is fundamental to all methods..." (Tymieniecka, p.xx)

The development of phenomenology began primarily with the work of the German philosopher Edmund Husserl who set about identifying methods of studying phenomena or experiences immediately presented to consciousness.

He believed that these experiences are all we can know with certainty. (Tageson, 1982) Heidegger applied Husserl's methods to the study of human existence itself. The use of phenomenological methods to study human existence has been labeled existential phenomenology. Other contributors in the history of phenomenological movement include Scheller, Marcel, Sarte and Merleau-Ponty.

The contemporary phenomenological movement may be classified as either structural or functional (Tageson, 1982). Structural phenomenology is concerned with qualitative descriptions of the inner world of the individuals who are studied. American phenomenologists exemplifying this approach include Adrian van Kaam (1966), Amedeo Giorgi (1970) and Ernest Keen (1975). Functional phenomenology attempts to establish replicable mathematical relationships between phenomenological variables. The works of Carl Rogers (1964) and Gordon Allport (1955) are examples of the latter classification (Tageson,1982). The research in this study is more appropriately classified as structural in that the emphasis is upon a qualitative description of courage, the experience of courage when one is coping with a chronic illness.

Phenomenology differs from traditional quantitative research methods in that it proposes that the phenomena of human behavior are not equivalent qualitatively with phenomena in the natural sciences. Methods other than a quantitative approach, therefore, are necessary. (Natanson, 1968)

Description of the phenomenological approach

Giorgi (1971) discussed phenomenology in terms of approach, method and content. He stated that the approach is characterized by "an attitude of openness for whatever is significant for the proper understanding of the phenomena" (p.9). The researcher concentrates on the phenomenon exactly as it is given to him without previous knowledge, other perspectives or predjudice. The method involves the processs of intuition, reflection, and description. The content of the phenomenon is the data of experience, its meaning for the subject, and the essence of the phenomenon. Experience is considered original data, not epiphenomena which need to be reduced to physical reality.

Giorgi (1975) identified the following characteristics of the phenomenological method in psychology:

1) Fidelity to the phenomenon as it is lived.

Those aspects of the phenomenon selected for study are perceived and understood within the context of the person experiencing the situation.

2) Primacy of the Life-World, that is, the every day world as it is lived by all of us.

3) Descriptive approach - description is made more rigorous by circumscribing attitudes, delineating aims and providing adequate contexts for all descriptions.

4) Expression of situation from the subject's perspective. It is the subject's viewpoint that provides the data for study.

5) Situation as a unit of research implies a structural approach. The lived situation is the basic unit of research and the primary variables are not physically defined. The meanings attributed to the situation are the significant factors.

6) Biographical emphasis - the key terms are formulated after contact with the data, not before.

7) Engaged researcher - the researcher plays an active role in the constitution of the research data. Presuppositions about the phenomenon are stated. Descriptions are transformed by the researcher in dialogue with the subject.

8) Search for meaning - in phenomenology the

meaning is the measured meaning and is obtained by systematic exploration.

The sources of description used in phenomenology include written description, dialogal interviews, observation of lived events and imaginative presence. Each of these sources utilizes specific methods of analysis. They are, respectively, protocol analysis, imaginative listening, perceptual description and phenomenological reflection (Valle, 1978).

The Use of Phenomenology in Nursing

While the nursing profession has maintained a commitment to humanism, which is defined as helping another to grow through caring (Ray, 1985) and a holistic approach to nursing care, it has at the same time formed a commitment to developing a body of knowledge, embracing traditional quantitative research methods as the means to this goal. However, traditional science is viewed by many as a threat to the humanistic ideas when science is utilized to quantify all of reality. The act of quantification disregards an essential aspect of human behavior that is necessary for a true holistic understanding of individuals. A tensions develops when nurses are encouraged to

distinguish between and separate objective and subjective reality. For instance, the SOAP (subjective, objective assessment plan) format for charting considers subjective data as merely a clue to the real, objective data. Compounding the problem is the nursing literature which lacks descriptions of patients' subjective experiences, yet nursing curricula assign many hours to teaching students the communication skills needed to obtain subjective data.

Oiler (1980) proposed phenomenology as a way of combining objective and subjective perspectives. She wrote:

> "The implication phenomenology holds for nursing, then, is essentially to enhance our reality by examining experience from multiple vantage points, and by making our awareness known to one another. Phenomenology offers a relation between science and philosophy in the unity of subjective and objective realities. We do not have to choose between science and humanism, but can understand nursing reality as a matrix of views and strive to awaken each to a full awareness and expression." (p. 151)

In addition to offering a solution to this dichotomous subject/object thinking, phenomenology offers "a basic and essential step in theory building. Indeed, considering the state-of-the-art of nursing theory development, it is the most crucial and immediate need." (Patterson & Zderad, 1976, p.82)

Phenomenological Studies in Nursing

Norris (1982) stated that qualitative methods have been recognized as having an important place in scientific work only within the last 20 years. There is increasing evidence that qualitative methods are often the most efficient or only method of studying an empirical situation. Although qualitiative research is called first-level inquiry by some researchers, the goals of qualitative research are described not necessarily as a precursor to experimental research but as a description of the inner perspective of people's experience or as theory development. The goal of first-level inquiry using qualitative methods may be seen as similar to Mannoia's (1980) abduction phase of science which is the logic of discovery. The process of discovery is the activity of moving from problem to a possible answer, the production of working hypotheses.

Nurses have used the phenomenological method to study questions which otherwise could not be studied. Examples of such questions include: "How does it feel to be dying? (Quint, 1966); "What are the common elements in the lived-experience of hope?" (Stanley, 1978); "What does it mean for a woman to lose her breast

and how does she come to terms with her change in physical appearance" (Quint, 1962); "What does being truly committed mean?" (Rugh, 1979); "What is the phenomenon we refer to or call 'restlessness' in nursing?" (Norris, 1975); "How do senders and receivers of touch perceive their interaction?" (Weiss, 1979); "What color is your pain?" (Steward, 1977); and, "From the perspective of the client, what is the essential structure of a caring nurse-client interaction?" (Reiman, 1983).

Assumptions

The following assumptions were identified for this study:

1. The experience of courage is a common human experience.

2. Common human experiences have like elements for individuals of the same developmental level.

3. Those like elements are expressed with the same word label.

Definition of Terms

The following terms were defined for this study:

1. Lived-experience of courage - a personal situation of courage which is identified and described by the participants. These are descriptions of an everyday occurance of courage which do not include attempts to analyze courage rather than describe the situation.

2. Common components- a description of a moment of the experience or theme of courage which, while expressed by a majority of respondents is also compatible with those descriptions of the experience of courage which do not express it.

3. Adolescent - any individual between the ages of 14 and 21.

4. Chronic illness - a condition which requires the individual to receive health care in a medical center at least three times and which has existed for at least six months.

Scope and Limitations

The scope of this study was defined by the ability of the participants to describe their experience and the ability of the researcher to extract the meaning and

structure of courage from the descriptions. A limitations of the study was the fact that courage, which is by nature an illusory and abstract concept, cannot be directly measured.

Summary

The concept of courage has been identified as an important variable in nursing, but one which is difficult to study because of its abstract nature. The qualitative approach of phenomenology was described as a conceptual orientation for studying courage in chronically ill adolescents. The research problem related to identification of the components of courage in chronically ill adolescents. Assumptions, definition of terms, scope and limitations for this study were identified.

CHAPTER 2

REVIEW OF LITERATURE

Although very few studies have been done on courage, there are some theoretical analyses, descriptions and conceptualizations of this concept. Several recurring themes and questions arise as one reads the literature on courage including such questions as: What is the relationship of courage to knowledge? to fortitude? to virtue? to humor? Are there different types of courage? Is courage common and necessary for survival or is it the property of a select few individuals? What factors effect the emergence of courageous behavior? Within the literature there are numerous literary descriptions of courage, tales of great heroism in the face of danger. The disciplines which have primarily dealt with the concept of courage are philosophy, psychology, and political and military science. Nursing literature on courage is limited. The following literature review presents the major descriptions and analyses of courage. While many of the descriptions and analyses seem contradictory, it is

anticipated that this study will reconcile some of the apparent contradictions.

Descriptions of Courage from Various Disciplines

Literary Descriptions of Courage

Throughout history there have been numerous literary descriptions of heroism and bravery. Such descriptions, exemplified by such a classic work as Homer's Oddessy have been offered in an attempt to explain and/or provide models of courage. The writings of Hemingway in such works as For Whom the Bell Tolls and The Old Man and the Sea provide examples in American literature of heroism in the face of an unfriendly world. Crane's Red Badge of Courage is an example of American literature which is a description of physical courage in war. The contribution that such works provide to an understanding of courage is in their universal recognition of the concept under varying circumstances. However such descriptions, by their very nature are idealized and they identify only those aspects of courage with which the author is concerned.

One unusual description of courage is a non-fiction work by Klein (1953) in which he surveyed 10,000 magazine articles describing personal experiences of

courage. Forty-nine accounts are included in his book. Klein observed that the magazines were replete with such examples and that many were from people who might be termed 'unfortunate' in that they faced physical, economic, social, or psychological difficulties. Klein described an inner strength that these individuals seemed to possess as a result of the difficulty they faced. He stated that in the process of dealing with problems they became far more superior individuals than they were before the hardship. Klein asserted that these individuals were not free of hesitations or fears, but often used their initial fear and frustration to gain greater determination. Eventually they were able to free themselves of fear to emerge as even stronger individuals. One key factor Klein identified is will. These individuals willed themselves to succeed despite the tremendous odds. In time, this will power became second nature, that is, their efforts were efficient and effective, so that they were reluctant to view their accomplishments as heroic. Although Klein did not attempt an extensive analysis of the lived situations of courage, he provided some interesting insights into the nature of courage as the situation of courage is lived out by the individual.

Descriptions of Courage from Observations of War and Politics

Much of the literature on courage has been written by those who observe war. Lord Moran in his book, The Anatomy of Courage (1967) described the courage of soldiers in the World War II. The book contains excerpts from a diary Moran kept as he served as a psychologist in the war and his reflections on that diary. Moran concluded that courage arises from fear and that "courage is a moral quality... It is a cold choice between two alternatives ... Courage is will power". (p.61) Moran asserted that since courage is will power, there is a limited supply and it can be used up in a situation such as war. When it is used up a man is "finished". Moran dealt with the question of whether courage is common to all or whether it as reserved for a few. He concluded that from his diaries there is little to support the idea that all men were heroes, but rather that most looked to a few for support and hope. Such a conclusion seems contradictory to the earlier thesis Moran raised that courage is present in different amounts, so that some may have used more than others but that all possess courage to some degree or they could not exist.

Another effort to describe the nature of courage is provided by Barrie's (1922) Rectorial Address to St. Andrew's University students following World War I. Barrie emphasized the imperative quality of courage by asserting that "all goes if courage goes...Unless a man has that virtue he has no security in preserving any other." (p.39) Barrie also viewed courage as something to be obtained, rather than an inate quality. An interesting exhortation Barrie made was to "be not merely courageous, but light-hearted and gay."(p.39) The use of humor as a "courage mechanism" rather than as a defense mechanism was proposed by Mishkinsky (1977).

Overstreet (1943) discussed means of obtaining courage in the crisis of war. His purpose was to aid those who cope with war while remaining at home. Overstreet viewed courage as a product of cultivated attitudes, habits and relationships rather than as a choice to be made. He asserted that some people have more courage because they have managed their entire lives in such a way that the ingredients for courage are present. Nine ingredients are identified and include: (a) a decisive will to organize and simplify life so that one is able and ready to act unencumbered by trivia; (b) self-respect; (c) knowledge of what is at

stake if courage is not displayed; (d) resourcefulness; (e) a view towards the future; (f) practicing courage; (g) maintenance of daily standards in activities; (h) companionship; and, (i) religion which includes a god figure, a set of beliefs, and fellowship with people of like minds.

Several authors identified other virtues as important to courage. Holmes (1943) viewed courage as being the same as morale, which includes the idea of freely using one's time and strength beyond for one's own advantage. This explication implies the will to do something one could get out of doing if one had no purpose but to live and be unhurt. Factors that Holmes identified as significant for courageous behavior include stamina, efficiency, happiness, possessions, beliefs, loyalties, and education. Mackenzie (1962) identified pursuit of truth and justice as the most powerful impulses to have moral courage along with common sense, feelings of compassion, and self-respect as valuable variables.

Kennedy (1956) discussed the challenge of political courage and described historical instances in which United States senators knowingly took dangerous political stances in order to uphold their personal

principles. Kennedy described the situations from the vantage point of one who has also experienced political pressures. His accounts are rich in the details which surround the situations so that the reader is able to reflect on the courageous situations. Nevins (1956), in the Forward to Kennedy's book stated that courage resembles a many-faceted diamond which changes depending on the setting. In defining courage much depends on the point of reference. Nevins asserted that courage must be exhibited in behalf of some large cause or rule for it to hold importance. He also implied that some courage is more constructive than others and can be viewed as part of a greater entity which he termed "character". Other traits Nevins pointed to which make up character include honesty, deep seriousness, a firm sense of principle, candor, and resolution.

While the above attempts to describe the nature of courage are helpful, none describes in a systematic way the lived-experience of courage. The descriptions are based upon observations of others who were labeled as courageous. They are limited in description of the internal dynamics occuring when an individual is courageous.

The Humanist View

The writings of several authors from related disciplines are included in this section because their general approach to the study of man involves a holistic, humanistic, perceptual or phenomenological, and person-centered approach. The authors to be discussed under this umbrella concept of humanism which is closely related to caring (Ray,1985) include May, Maslow, and Tillich.

The ontological nature of courage is described from the existentialist perspective by Tillich (1952) who asserted that courage is an ethical reality found in all of human existence and ultimately in the structure of being itself. Courage is the affirmation of self in the face of human anxiety which is the result of the despair of possible pain, suffering, and death. Courage is viewed as providing a balance between the individual, alone and fearful and possessing values and commitments, and the world, the source of anxiety.

May (1975) concurred with Tillich's assertion that courage is ontological, essential to our being. He stated that in human beings courage is a necessity to being and becoming. May also implied that courage is an assertion of self, a commitment. He viewed courage as

the foundation that underlies and gives reality to all other virtues and personal values such as love and fidelity.

May identified and described four types of courage: physical, moral, social, and creative. Physical courage is viewed, traditionally, as the most primitive form of courage; and, ideally, as the use of the body to gain sensitivity. Moral courage is viewed as the identification, through one's own sensitivity, with the suffering of one's fellow human beings. Moral courage involves actions based upon empathy. Social courage involves the risking of oneself in the hope of achieving authentic intimacy, increasing openness in a relationship. Creative courage is the discovering of new forms, symbols, and patterns upon which a new society can be built. Artists and writers who move beyond current limits to bring meaning to existence are examples of creative courage.

Maslow (1971) discussed courage in the context of human growth. He identified "versions of courage": stubbornness, independence, self-sufficiency, arrogance, ego-strength. He asserted that courage aids one in being attracted to mystery, novelty, ambiguity,

and the unusual, rather than being fearful, suspicious, and anxious. Maslow asserted that trust involves courage.

Psychological Studies of Courage

The discipline of psychology has only recently studied courage in a systematic fashion. Two systematic sets of work are found in psychological literature, each approaching the question of what is courage from very different perspectives. Rachman (1978) utilized traditional, quantitative methods in his studies of courage while Asarian (1983) utilized a phenomenological method to identify the structure of courage.

Rachman's Courage as a Mirror Image of Fear

Rachman (1978) provided a beginning study of courage as it relates to fear and applied Lang's three system model of fear to this concept. The three components of the system are the subjective experience of apprehension, associated psychophysiological changes and attempts to avoid or escape from certain situations. Rachman suggested that where fear is being assessed, courage can also be assessed.

From Rachman's discussion of courage several variables which may have a significant bearing on the emergence of and/or the tendency for courageous behavior can be extracted. They include:

1. A perceived controllability. Controllability refers to the individual's sense of his capability to reduce the likelihood of an aversive event and/or its consequences.

2. A sense of competence, ability to master stress, and/or a sense of self-confidence obtained through training.

3. A tendency to habituate-to adapt to repeated stimulation of the same kind.

4. Contagion. An imitation of courage stimulated by the example of others. Rachman asserted that use of a skilled model is important in the preparation and execution of difficult tasks.

5. Required helpfulness. Such helpfulness is the assignment of socially responsible tasks.

6. Situational demands. These include a sense of responsibility to self and others, the effect of group membership and morale, and the need to avoid ridicule or disapproval.

Rachman's conceptualization of courage was utilized in a study by Cox, Hallam, and Rachman (1983) of the performance under stress of decorated and non-decorated bomb-disposal operators. The seven subjects in the decorated group, hypothesized to be 'braver', maintained lower cardiac rates when making discriminations under threat of shock than did the seven non-decorated, but equally experienced and successful operators. There were no differences in the subjective reactivity reported or in the performance of the two groups. The researchers asserted that the findings indicate that courageous actors have a different pattern of physiological arousal during stress.

The attribution of courage to self or others was studied by Evans and White (1981) utilizing Rachman's conceptualization of courage in an attempt to formulate an empirical definition of courage. The subjects were 124 adolescents who viewed a film of an actor/actress handling a snake and then ranked their own and the actor's fear and courage. Two modes of attribution of courage were viewed as naive, i.e. attributing bravery if one is afraid oneself or identifying bravery with fearlessness. The third mode, considered a sophisticated mode, occurs when a person who is fearful

nevertheless approaches a feared situation. The researchers found that use of the more sophisticated mode increases with age; however, the naive mode of "Me fearful, therefore, you brave" does not reliably decrease and probably continues to be used regardless of age. The researchers concluded that an empirical definition of courage is difficult to formulate and requires more study.

Asarian's Phenomenological Study of Courage

A recent study by Asarian (1983) provided the only phenomenological study of courage found in the literature. Asarian's purpose for the study was to identify the essential structure of courage. Because of the study's significance to this research, a detailed description is provided. An overview of methodology, discussion of findings, and implications of the study for this research are discussed.

Methodology. Asarian utilized a multi-level data collection procedure of informal interview, written protocol, and formal interview of three pairs of observers and actors in three unrelated situations of courage. The observers were asked to identify a courageous person and describe the situation in which

the courage took place. The actors were asked to describe a situation in which they were courageous and to describe a situation in which they perceived themselves as lacking courage. Two of the three situations were categorized by Asarian as assertive determined, involving a direct assault upon a challenge. In one situation the courageous actor was a prison guard who acted to contain a prison riot, in the other situation the courageous actor quit his job to move closer to the family's home despite probable economic hardship. The third situation which was analyzed was classified by Asarian as dignified acceptance, involving acceptance of personal limitations, concern for others, and an openness and sensitivity to one's own feelings. The situation was one in which the actor dealt with a terminal cancer. The ages of the participants, both actors and observers ranged from late thirties to mid-fifties.

In data analysis Asarian utilized an elaborate, multilevel qualitative approach including analysis of individual meaning units, reflective analysis, elaboration of the protocol, temporal organization, situated structure, general structure and, finally, an essential structure of courage.

Findings. Asarian identified the essential structure of courage as:

> "an intended, arduous, behavioral commitment to values despite formidable conflict, fear, and suffering--if need be death--for the intersubjective significance and intrinsic worth these values are perceived to possess. All of this meaning is given in the realization to betray one's commitments would destroy self-respect and self-worth. It is a radically social phenomenon whose theoretical foundation is grounded in the perception of a significant other."(p. 135)

Asarian stated that the the "being of courage" requires four co-present motivational factors: (a) a fidelity to values and extension of commitment to those values, (b) intersubjectivity of this social phenomenon, (c) an intrinsic satisfaction and meaning in the struggle itself, and, (d) fear of the alternative, negative consequences of not acting courageously in terms of the individual's definition of self.

Asarian identified "phases of becoming courageous" which include a pre-courageous situation and a living out of the courageous decision. The pre-courageous situation is one in which there is first an initial tension in a challenge to the individual's values and then an acceptance of the courageous option involving adoption of a stance, formulation of a decision, and

disclosed but unclear behavior. The living out of the courageous decision contains four sub-phases:

1. Explicit struggle includes progressive-regressive movement and coping with consequences and counter-finalities of the decision.

2. Gradual clarification involves a clarification of values, emergence of a single-mindedness, and an extension of commitment to the values identified.

3. Affirmation of choice results in joy of accomplishment and a feeling of release from pressure.

4. Reflective recognition of stature includes a process of labeling the situation as courageous and results in self-esteem, appreciation of one's humanity and a sense of substantiality.

Implications. Asarian claimed several implications for his study both in terms of methodology and understanding of the phenomenon. Asarian identified three potential paths to access courage: the courage perceived by the actor, the courage observed by another, and the perceptions of a situation where courage was lacking by a courageous individual. Asarian found that simply asking individuals to describe a situation in which they were courageous did not yield data which was rich in description because the actors were reluctant or

unable to identify a courageous act. In the pilot study conducted for the present study, however, such was not the case. The pilot study, described in detail in Chapter 3, was conducted with chronically ill adolescents and the difference in their ability to describe a situation may have been due to the social nature of courage which Asarian identifies. The adolescents may have had many individuals identify them as courageous because they were frequently facing difficult and even life-threatening situations over an extended period of time in a setting where many people including family and health care professionals observed them.

Asarian stated that his study has made two unique revelations about courage. The first, the social nature or interpersonal quality of courage, involves a courage in which the actor's judgement is socially oriented and socially revealed. The courage is sustained by others and it reciprocally inspires and encourages both the actor and the observer of the situation. The second revelation of Asarian's study involves the reciprocal relationship of creativity and courage in which something new is created as a result of the courageous act and in which the expanded perception of the

situation is created. According to Asarian, neither courage nor creativity exist without the other. These findings provide clarification of both Tillich's and May's discussions of courage.

Study questions about the common nature of courage and courage and alienation have been identified by Asarian from his research. Although some previous literature has identified courage in ordinary, everyday situations, Asarian reaffirmed this finding. Especially in the situation of the actor dealing with a terminal illness, Asarian found that courage was not so much the confronting of death as it was fully living life. Further study of courage in relation to alienation was proposed because in the situations described courage drew the individuals' commitments and the world together by providing inspiration to the observers and contentment and meaning to the actors.

Nursing Literature

The nursing literature on courage is limited and includes no studies of courage from the perspective of the courageous individual. Little and Carnevali (1976) discussed courage as a coping mechanism which involves risk taking. They viewed the lack of courage as a

coping deficit, an often missed diagnosis. Courage was viewed as a subjective experience which must be measured in terms of the client's version of the degree of risk. "Data on the client's perception of risk is the yardstick on this variable." (p.244)

Lanara (1974) examined the concept of heroism found in the literature in order to relate heroism to nursing philosophy. The study suggested that heroism arouses the spirit of caring in nurses and that nursing offers many opportunities for the nurse to be heroic. Lanara identified love as the noblest form of heroism. Lanara asserted that heroism requires both a situation which holds the potential for heroism and an individual willing to take the challenge of acting in a heroic manner.

Keeling (1978) described a case study in which a terminally ill man aided Keeling in accepting death. That process is titled "giving and getting courage" and Keeling stated, "Mr. Lair once told me he hoped his suffering would in some small way help another person. I think he knew, even before I did that I was that person."(p. 41)

Related Literature

Concepts which are related to courage include discouragement, encouragement, and mastery. Discouraged individuals, according to Dinkmeyer and Dreikuss (1963), have the opposite convictions of courage and are unable to perceive themselves as possessing the ability to solve problems, find solutions, or win battles. Such individuals have no confidence in themselves or in life. Dinkmeyer and Dreikuss distinguished between such a total lack of confidence and feelings of inferiority where a potential for growth exists.

Dinkmeyer and Dreikuss (1963) viewed encouragement as providing security and a sense of being worthwhile. They have identified methods of encouraging children including: valuing the child; showing faith; recognizing a job well done; giving recognition for effort; developing skills sequentially and psychologically paced to permit success; recognizing and focusing on strengths and assets; and, utilizing the child's interest.

Droske and Francis (1981) discussed mastery in the context of preparation of children for hospitalization and procedures. Mastery was defined as active participation by the child in developing a feeling of being in control of oneself and one's environment.

Mastery is obtained through identification and practice of behaviors that can increase the child's sense of being in control while undergoing procedures.

Summary

The review of the literature revealed numerous conceptualizations of courage based upon observations of others. It also contained philosophical discussions of courage. There are, however, very few systematic studies of courage. Of the studies which were carried out in a systematic manner, only one approached courage from the perspective of the individual. No studies have looked at the experience of courage in chronically ill children.

While many factors were mentioned as influencing courageous behavior, the literature seemed contradictory in identifying which factors are of importance, which occur first, and whether courage is a quality which is inate or can be acquired. Indeed, the very nature of courage has been limitedly defined.

CHAPTER 3

METHODOLOGY

The design for this study was descriptive and used phenomenological methods. The specific method used was protocol analysis of transcribed tape-recorded interview descriptions of courage obtained from nine chronically ill adolescents between 14 and 21 years of age. Using this approach the researcher utilized unstructured interview methods to obtain spontaneous descriptions of the subjective experience of courage in a specific situation. These descriptions were analyzed in order to identify the common elements of courage and to derive the essential structure of courage in chronically ill adolescents.

Setting

The setting for this study was the in-patient units of a 416 bed children's hospital which is one of three state hospitals within a large university medical center in the Midwest. The participants were identified through the adolescent in-patient unit and through several special care units.

The setting for initial contact with participants varied. Generally they were seen in their semi-private hospital room in which visitors, staff, and/or other patients may have been present while the study was being explained and consent to participate was obtained. On two occasions the participant was alone in protective isolation during the explanation.

Population and Sample

A purposive sample (N=9) was selected for inclusion in the study from the population of chronically ill adolescents receiving care in the children's hospital. Potential participants were identified in consultation with the head nurse and/or nurse clinician on each unit based on criteria adapted from recommendations by Kruger (1981):

1. The participants will speak and read English.
2. The participants will be able to identify at least one recent situation in which they perceived themselves as courageous.
3. The participants will indicate a willingness to discuss their courageous experience freely and openly.

These criteria were selected on the basis of Valle and King's (1978) statement that "experience with the

investigated topic and articulateness suffice as criteria for selecting subjects." (p.58)

The following additional criteria were identified based upon definitions related to the problem statement. The participants will:

1. Be between the ages of 14 and 21.

2. Have a chronic illness as evidenced by their receiving health care at least three times during the past year for the same disease and having the condition for at least six months.

An effort was made to include participants with both life-threatening and non-life-threatening conditions so that when common elements of courage were identified the elements would not be confounded by the prospects of impending death.

Participant Welfare

In compliance with the rules and regulations of Texas Woman's University Human Subjects Review Committee, the following steps were taken.

1. Prior to the initiation of the study, permission to conduct the study was obtained from the Texas Woman's University Human Subjects Review Committee and the Graduate College (Appendix A).

2. Prior to collection of data, Institutonal Review Board approval and agency permissions were obtained from the health science center in which the data was collected (Appendix B).

3. Potential participants and their parent, if the participant was a minor, were given a verbal and written explanation of the purpose of the study (Appendix C). The process of identification of the adolescents as potential participants was discussed as was the fact that participation was voluntary and could be stopped at any time. The verbal description of the data collection procedure included the following: (a) the participant will be asked to describe a recent situation of courage that he experienced and the feelings and thoughts which accompanied that situation; (b) the situation to be discussed will be self-selected so that it should not be a situation which the participant is emotonally unable to handle; (c) the information will be obtained by audio-tape recorded interview; (d) the participant may be asked to review the study findings to validate them.

Data Collection Procedure

Preliminary Participant Preparation

After consent to participate was obtained, an appointment was made to conduct the interview at a time and place convenient to the participant. The participant was asked to think about the lived-experience of courage and a written description of the data generating questions was provided. (Appendix D) Questions regarding the conduct of the research were answered; however, questions relating directly to the phenomenon of courage were deferred in order to avoid interjecting the researcher's biases. Some of the participants seemed eager to relate their experience of courage at the time of initial contact to validate that it was an "appropriate" situation to describe. The researcher listened to this preliminary description for as short a time as was seemly, encouraging the participant to wait until the description was being tape-recorded for further details.

Conduct of the Interview

An open-ended interview was conducted by the researcher utilizing three data generating questions

which were adapted from Stanley's (1978) study. The questions were:

1. Please describe a situation in which you were courageous.

2. Describe your experience exactly as you remember it including your thoughts, feelings and perceptions as you remember experiencing them.

3. Please continue to describe the experience until you believe it is fully described.

Clarification questions were asked at appropriate times during the course of the interview to provide the researcher with as clear a picture of the situation as possible. Suggestive or leading questions were avoided. An audio-tape recording was made of the interview for later transcription and analysis.

The interviews were conducted in a place which was convenient to the participant and which afforded privacy and as much quiet as possible. The interview setting was a private office on the adolescent unit in most cases. Two interviews occurred in the participants' hospital room which was set up for protective isolation. Every effort was made to ensure that the participant was relaxed and comfortable during the interview. When the interview was conducted away from the participant's

room, the staff was notified so that the participant did not miss medications or physician visits. Very few interuptions occurred during the interviews. An effort was made to ensure that the participant was able to assume a comfortable position during the interview.

Pilot Study

A pilot study was conducted with an initial purposive sample of 10 chronicllly ill adolescents between the ages of 16 and 20 and one chronically ill young adult, 24 years of age. The participants were asked to write on the following questions:

1. Describe a situation in which you were courageous.

2. Describe your experience exactly as you remember it including your thoughts, feelings and perceptions as you remember experiencing them.

3.Continue to describe the experience until you believe it is fully described.

During the data collection period it became apparent that the participants were having difficulty writing about the courageous situation as only one written description was obtained. Participants were, however, able to identify a situation of courage when

interviewed. A combination of factors seemed to effect the ability to write about a courageous situation. Two participants had an intravenous medication needle in their writing hand. Some of the participants seemed uncertain of their writing skills. Some participants' situation of courage involved their life-threatening illness and, although they were able to verbally discuss the situation, writing about it was difficult. At the end of the data collection period, one written description and three verbal descriptions of courageous experiences were obtained for data analysis. The four descriptions were elaborate, intricately detailed descriptions of courage. The tape recorded verbal descriptions were transcribed and analyzed in the same manner as the written description.

Data analysis was done using Colaizzi's (1978) procedure described in the present study with the exception that validation of formulated meanings was not done; and, the three final steps of the procedure were not done because of time limitations and the limited number of protocols obtained. Within the four protocols, 221 significant statemets were identified of which 200 were used after repetitions were eliminated. Six categories of themes were identified. They were

situation, reactions to the situation, attempts to cope with the situaion, relationships with others, transcendence, and signs of improvement in the situaion. Under each theme cluster, several sub-themes were identified.

Data Analysis

The analysis of the data was done using a procedure adapted from Colaizzi's (1978) procedure. A description follows:

1. All descriptions (protocols) were listened to several times in order to acquire a feeling for them, a making sense out of them. In addition, the researcher transcribed the tapes to written form to increase familiarity with the content of each protocol.

2. For each protocol, significant phrases or sentences that directly pertained to the investigated phenomena were extracted. This is known as <u>extracting significant statements.</u> Although it was planned that repetitions would be eliminated, the repitition of statements seemed to add an emphasis which the participant desired to communicate, so they were retained.

3. Each statement was transposed to a more general formulation, a restatement.

4. The meaning of each significant statement, the formulating meaning, was derived. While moving beyond protocol statements, the meanings formulated did not sever the connection with the original protocols. The restatements and formulated meanings were validated by two doctorally prepared individuals who have experience with qualitative research. These judges read both the restatements and the formulated meanings and compared them with the original protocols to validate that the meaning of the significant statement was retained.

5. The formulated meanings were organized into clusters of themes in order to allow for the emergence of themes which were common to all of the participant's protocols. Again to avoid making an unwarranted "leap" beyond the data, the clusters of themes were referred back to the original data for validation by the same judges who reviewed the restatements and formulated meanings. These individuals were asked to decide whether there was anything in the original protocols that was not accounted for in the clusters of themes and whether the clusters of themes proposed anything which was not implied in the original protocols.

Discrepancies present in the themes were not eliminated since they could be logically inexplicable, but existentially real and valid (Coliazzi,p.61). Data which did not seem to fit was not ignored nor were hypotheses prematurely generated which would eliminate the discordance.

6. The results were integrated into an exhaustive description of courage in chronically ill adolescents.

7. The exhaustive description of courage was formulated into as unequivocal statement of the fundamental structure of courage in chronically ill adolescents as was possible.

8. To finally validate the findings, three of the participants were asked to compare the findings for congruence with their lived-experience.

Validity and Reliability

Validity was established during three stages of data analysis. Two validators reviewed the data following the formulation of meanings and identification of theme clusters. Both individuals were were doctorally prepared nurses. One was experienced in the use of phenomenological methods, the other in the use of grounded theory. Validity was also established

following completion of data analysis by presenting the conclusions to three research participants to ascertain whether the conclusions accurately reflected their experience of courage. "The consistency or reliability is one of integrated variations of perspectives on an empirical event." (Fisher, 1978).

CHAPTER 4

ANALYSIS OF DATA

This chapter presents a description of the sample and findings of the study. The findings are described in terms of each step of data analysis and include a description of the situations of courage, a description of significant statements and restatements, formulated meanings, themes, and the exhaustive description of courage in chronically ill adolescents. The chapter concludes with a summary of the findings.

Description of Sample

The sample of participants who agreed to participate in the study and whose protocols were analyzed through all steps of the procedure consisted of 9 chronically ill adolescents between 14 and 21 years of age. The sample was a purposive sample identified in consultation with nursing personnel who were familiar with the individuals and knowledgeable about the nature of the study, including criteria for inclusion in the study.

Twelve potential participants were approached for possible inclusion in the study. One participant was unable to identify his experiences as being courageous, although many of the staff perceived him as such. One participant primarily analyzed the concept of courage throughout the interview rather than describing her situation, so the protocol was not included in analysis. Technical difficulties with the tape-recorded interview of one participant precluded inclusion in the study since the individual was unavailable for a second interview.

Of the nine participants whose protocols were analyzed, 4 were male, 5 were female. The race of 8 participants was white, one was black. Regarding the family status of the participants: all resided with one or both parents; none of the participants were married; one was engaged to be married; one had an infant less than one year of age. Five participants were enrolled in high school; 1 had been in college until his health condition required withdrawal; 3 had completed high school and were either working or staying home.

The nine participants were hospitalized for a variety of treatments and/or procedures including surgery. All of those participants who were admitted

for a surgical or other procedure were well into the recovery period at the time of the interview. None of the participants were on activity restrictions and one was receiving intravenous medication during the interview. Table 1 describes the demographic data for each participant whose situation was utilized throughout the analysis.

Table 1

Description of Sample by Demographic Variables

(N =9)

Age	Sex	Diagnosis	Reason for Admission
21	M	Chronic Renal Failure	Renal Transplant
20	M	Cystic Fibrosis	Pneumonia
19	F	Recto-Vaginal Fistula	Colostomy closure
18	M	Leukemia	Bone Marrow Transplant
18	F	Pulmonary Stenosis	Angioplasty
15	M	Atrial Stenosis	Surgical correction
15	F	Chronic Renal Failure and Burns	Contracture correction
14	F	Scoliosis	Harrington Rod Placement
14	F	Leukemia	Chemotherapy

Findings

Situations of Courage

Although participants were informed that they could choose any situation, they all chose to describe a situation related to their health/illness condition. All of the situations occurred over a period of several months or years. The general theme of the situations for the 9 protocols were:

- Having open heart surgery, knowing about it and all that led up to it
- Having leukemia and dealing with the procedures related to a Bone Marrow Transplant (BMT)
- Dealing with treatments for leukemia and the effects of treatment
- Having a second renal transplant and being different from others
- Having cardiac procedures done
- Having a renal transplant
- Having surgery for and adjusting to a colostomy
- Gaining acceptance of having cystic fibrosis and assuming responsibility for care
- Having surgery for scoliosis.

Extraction of Significant Statements

Within the 9 protocols, 889 significant statements were identified. Repetitions were not eliminated, since it became apparent during the reading of the protocols that repetitions were utilized by the participants for emphasis. The significant statements primarily consisted of phrases or complete sentences. The significant statements were reformulated into a more generalized form in order to formulate the meaning of each statement. An effort was made to maintain a close connection between the restatement and the original statement. This process was validated by the two doctorally prepared judges. Because the amount of data to be analyzed was enormous, examples of restatements rather than each restatement is described in this study. Table 2 presents examples of restatements from each protocol.

Formulated Meanings

The significant statements and restatements were studied to arrive at a sense of their meaning, the formulated meaning. Each formulated meaning was developed with consideration of the statements which preceded and followed it so that the context was

maintained. Concepts, labels, and processes were identified for each statement. Because of the tremendous amount of data for which meanings were formulated, two examples only, from each protocol are presented in Table 2. Each example includes the extracted significant statement (SS), the restatement (RS), and the formulated meaning (FM).

The formulated meanings were validated by the two doctorally prepared judges to assure that the formulated meanings, while moving beyond the protocol statements, did not sever all connections with them. The formulated meanings were validated with a minimum of change. Changes carried out as result of the process of validation were usually done to increase precision or to expand the meaning to be more inclusive of relevant concepts. For example, the term "different" was changed to "threatening"; "decision to follow intuition" was expanded to "decision to trust and follow intuition."

Table 2

Examples of Significant Statements, Restatements, and Formulated Meanings

Examples from C:

SS: The most scarey part was being in the operating room and being in the waiting room and waiting.

RS: The most frightening aspects of situation were being in operating room and waiting in the surgical holding area.

FM: Anxiety and fear were most acute during the waiting time immediately prior to surgery.

SS: My mom just held my hand and talked to me. That made it better.

RS: Mother holding hand and talking improved situation.

FM: Touch and verbal experessions of caring by mother decreased feelings of despair to a tolerable level.

Examples from B:

SS: Just live your life the best you can and try and make the most of it.

RS: Live life the best way possible and experience as much of life as possible.

FM: The only course of action is to adopt an attitude of wanting to deal with problems and reaching for the best, the optimum, in each day.

SS: They just seem like a part of my everyday life now.

RS: Procedures seem routine part of life presently.

FM: Has become so accustomed to complicated medical regimen that it seems routine and normal and expected and, therefore, not so much of a concern.

(table continues)

Table 2 (continued)

Examples from S:

SS: I'm going no, I'm not nervous, I know it's going to go alright. But, I was really scared. I was just trying to act brave and tough it out.

RS: Denied nervousness, stated knew would be alright, but was scared. Tried to act brave and tough.

FM: Experienced inner turmoil, but tried not to reveal fear to others. Wanted others to believe was brave and tried to endure situation.

SS: A lot of people said they see a light when they leave and they come back, but I don't remember.

RS: Although others have related experience of viewing a light when close to death, can't recall such a vision.

FM: Possesses a sense of wonder and curiosity in struggle to gain a personal knowledge of cognitively known occurrances during surgery.

Examples from L:

SS: I really was caught off guard then and I started getting tense pretty fast.

RS: Lack of anticipation of situation resulted in rapid onset of tense feelings.

FM: Rapidly began to feel emotional and physical responses of nervousness when event unanticipated.

SS: But I stayed real calm about it.

RS: Remained calm about impending surgery.

FM: Feelings of nervousness, while present were under control.

(table continues)

Table 2 (Continued)

Examples from T:

SS: I just talked myself out of it, I guess. Put my mind on something else and the scaredness went away.

RS: Told self of other things and the feelings of fear dissipated.

FM: Conducted a self-dialogue about other things which was effective in dissipating feelings of fear.

SS: I was sitting there saying, "I went through this?!"

RS: Sat and thought "I went through this!?"

FM: Felt amazement and a sense of mastery from effectively handling the difficult situation.

Examples from M:

SS: I knew he'd take care of everything and it'd be alright. I had trust in him.

RS: Believed physician was competent and that outcome would be acceptable. Trusted physician.

FM: Trust in physician provided reassurance security.

SS: I like to draw, and coloring. I mostly did that to keep my mind off it (pain). I'd do it just as long as I could and then when I'd get tired, I'd just go to sleep and I wouldn't have so much pain.

RS: Enjoys artwork and used it to avoid thoughts of pain. Did artwork as long as possible and then was so tired that would be able to sleep without as much pain.

FM: Pain was managed by conscious efforts through distraction activity and avoiding thinking about it. Maintained distracting activity long enough to tire and then sleep was means of relief from pain.

(table continues)

Table 2 (continued)

Examples from A:
SS: I go "Well, I don't want to take the treatments. I'd just rather keep my hair."

RS: Tells health care personnel (HCP) that would rather forego treatments and keep hair.

FM: Tests the reality, severity of the situation by focusing on non-life threatening consequences of the disease rather than the disease itself.

SS: They go "You must have treatments, or you'll die."

RS: HCP relate that without treatments, will die.

FM: The reality that the problem is severe is learned through hearing the dire consequences of non-treatment.

Examples from D:
SS: I mean it kind of seemed funny coming in because I didn't feel sick or anything.

RS: Being admitted to Bone Marrow Transplant (BMT) unit when didn't feel sick seemed funny.

FM: Felt strange, unsure about the necessity for doing what was expected. Experienced an incongruity between the necessity of admission and personal experience of feeling well.

SS: It just really seemed annoying, that going.

RS: Going to radiation therapy seemed annoying.

FM: The process of preparing for and undergoing treatment was aggravating, an unwelcome intrusion.

(table continues)

Table 2 (continued)

Examples from E:

SS: You start shaking every once in awhile when you start thinking about it. You get real scared.

RS: Physically shakes occasionally, feels very scared when does think about surgery.

FM: Experiences physical tremors, feelings of fear when thoughts are focused on surgery.

SS: Yeah, and you start thinking. You start thinking a lot, wondering how it would affect everybody, how it would affect your parents if you were to die.

RS: When thinks about surgery, thinks about the effects of death on others, especially on parents.

FM: Thoughts about the scheduled surgery include scenarios of the possible affects of own death on others.

Theme Clusters

The formulated meanings were organized into themes and clusters of themes to allow for the emergence of the themes which were common to all of the participants' protocols. The themes were referred back to the original, numbered, protocol statements in order to avoid making an unwarranted "leap" from the original data and in order to gain a sense of the commonality of the themes (Appendix E). The themes and their relationship to each protocol's significant statement was again validated by the two doctorally prepared nurses.

The theme clusters which emerged fell into nine categories including: (a) Characteristics of the situation, (b) Evaluation process of the situation, (c) Coping, (d) Responses to the situation, (e) Relationships with others, (f) Transcendence, (g) Dealing with procedures, (h) Perceptions of surgery, and (i) Resolution. Thirty-one theme clusters were identified. (see Table 3)

Table 3

Categories of Themes and Theme Clusters

Theme Category 1: Characteristics of the Situation
- -Theme Cluster 1A: Gaining an Awareness of the Situation (Table 4)
- -Theme Cluster 1B: Physical Changes (Table 5)
- -Theme Cluster 1C: Time Perceptions of the Situation (Table 6)

Theme Category 2: Evaluation Process
- -Theme Cluster 2A: Evaluation Process of the Situation (Table 7)

Theme Category 3: Coping Themes
- -Theme Cluster 3A: Coping Through Thought Processes (Table 8)
- -Theme Cluster 3B: Coping Through Avoidance (Table 9)
- -Theme Cluster 3C: Coping Directly with the Situation (Table 10)
- -Theme Cluster 3D: Coping Through Clarification of the Situation (Table 11)
- -Theme Cluster 3E: Factors Effecting Coping (Table 12)

Theme Category 4: Responses to the Situation
- -Theme Cluster 4A: Behavioral Responses (Table 13)
- -Theme Cluster 4B: Unpleasant Emotional Responses (Table 14)
- -Theme Cluster 4C: Pleasant Emotional Responses (Table 15)

Theme Category 5: Relationships with Others
- -Theme Cluster 5A: Relationships with Health Care Personnel (Table 16)
- -Theme Cluster 5B: Relationships with Family (Table 17)
- -Theme Cluster 5C: Influence of Others (Table 18)
- -Theme Cluster 5D: Influence of others with similar condition (Table 19)
- -Theme Cluster 5E: Informing Others (Table 20)

(table continues)

Table 3 (continued)

Theme Category 6: Transcendence Themes
- -Theme Cluster 6A: Hope for Something (Table 21)
- -Theme Cluster 6B: Sources of Hope (Table 22)
- -Theme Cluster 6C: Faith (Table 23)

Theme Category 7: Dealing with Procedures
- -Theme Cluster 7A: Anticipation of the Procedure (Table 24)
- -Theme Cluster 7B: Fear (Table 25)
- -Theme Cluster 7C: Medical Technology (Table 26)
- -Theme Cluster 7D: Pain (Table 27)
- -Theme Cluster 7E: Positive Feelings Related to Procedures (Table 28)
- -Theme Cluster 7F: Distraction Methods for Procedures (Table 29)
- -Theme Cluster 7G: Evaluation Process for Procedures (Table 30)

Theme Category 8: Perceptions of Surgery
- -Theme Cluster 8A: Perceptions Prior to Surgery (Table 31)
- -Theme Cluster 8B: Perceptions Immediately Following Surgery (Table 32)
- -Theme Cluster 8C: Recovery Period (Table 33)

Theme Category 9: Resolution of Situation
- -Theme Cluster 9A: Resolution (Table 34)

Characteristics of the Situation Themes

Characteristics of the situation theme clusters which emerged included gaining an awareness of the situation, physical changes, and time perceptions. In gaining awareness of the situation (Table 4) an event or series of events occurred which was initially difficult to comprehend or perceive as real. No major physical symptoms had been experienced prior to being informed of or becoming aware of the situation. Medical procedures were done to evaluate and verify the health-related condition. Alternatives were evaluated and plans were made for treatment. Evolution of the situation was slow and/or unexpected and/or progressively severe.

The physical changes themes (Table 5) were related to the changes' effects on appearance, daily living, and interactions. The physical changes were: more concern than the actual disease; a concern when interacting with others; unwanted; a source of self-consciousness; affecting activities of daily living and quality of life.

Time perceptions of the situation were related to waiting periods prior to or between procedures. Such time periods were a time of uncertainty and evaluated as long or short. Time perceptions were also related to

length of hospitalization and the dynamic nature of the situation. Participants were able to identify when in time the situation changed. Time perceptions were significant in the progression of the situation. Table 6 describes time perception themes and examples of significant statements.

Table 4

Theme Cluster 1A: Gaining Awareness of the Situation

An event or series of events precipitates courage:
- -My first renal transplant.
- -My surgery and knowing about it and all that led up to it.
- -When I first found out about the leukemia.

Initial difficulty perceiving/comprehending the situation as real:
- -I wasn't taking my disease seriously.
- -I kind of kept in my mind that, nah, there's nothing wrong with me that bad.

No prior major physical symptoms:
- -I just led a normal life like any other kid.
- -I'd been running a couple of miles a day--working it up and I couldn't tell there was anything wrong with me.
- -Starting out when I first found out I had it, I went in for a sore throat.

Underwent procedures to verify and/or evaluate situation:
- -They did the heart thing first, the catheterization. Then they said they had to do it (the surgery).
- -I started going every three months now, going back for checkups.

Alternatives evaluated and plans made for treatment:
- -I found out about it when I was in the sixth grade and I couldn't get anything done about it until I moved.
- -So they tried it again without the colostomy and it just didn't work, so I came back in February.
- -And basically it got down to around April where they said, "Well, let's talk about dialysis."

(table continues)

Table 4 (continued)

Situation evolved slowly/unexectedly/progesssed in severity:

-The first time I heard of the colostomy was in October of '83.
-I had strep throat and the progression has gone real slow as far as it getting worse or anything.
-They did a blood test and they called me the next day to come in and check it and they said something was abnormal.
-When I turned thirteen, that's when I started having more trouble.

Table 5

Theme Cluster 1B: Physical Changes

More concern than actual disease:
- -(I was thinking) this is my last normal day without a scar.
- -I didn't worry about the leukemia so much. I just worried about losing my hair.

A concern when interacting with others:
- -When it (hair) fell out I moved to a new school and that was really hard.
- -Sometimes at school they make fun of me. Some of them understand, but some of them don't.

Unwanted:
- -I thought, "Oh, God, I don't want one of those (colostomys)".
- -And I'd be thinking if I didn't have all these problems I'd be just like them and they couldn't make fun of me.

Source of self-consciousness:
- -Everyone looked at me real funny.
- -And have other people see this I've got to wear and not stare at me.

Effected activities of daily living/quality of life:
- -I could work just fine, but I was so worn out by the end of the day I just couldn't do anything but sit at home.
- -I can go swimming. I went swimming with it. You can do just about everything with it.

Table 6

Theme Cluster 1C: Time Perceptions of the Situation

Waiting periods were time of uncertainty:
- -So, I go back and I'm not running--I'm sitting around just in case (they find something wrong).
- -I couldn't use her kidney. I was put on the waiting list then...I couldn't believe it (when they called). I was all geared up for it to be months.

Waiting periods were evaluated as being long or short:
- -It's about 5 hours now on dialysis. That's awful long.
- -Because when they told me it (closing of colostomy) wouldn't be until June, I'm going "It's so long!"
- -It wasn't that long after, I realized I was making it longer than it (time having colostomy) was.

Waiting periods were related to length of hospitalization:
- -I couldn't wait to get home because I'd been in the hospital so long.
- -I'm becoming very uncontented in the hospital every now and then. It's just I get kind of grumpy.

Situation and reactions to it are dynamic:
- -Since then, I'd come up here about every month or two just to get blood tests...Then it just went like that until about 37 days ago and that's when I came in for the BMT.
- -It (kidney) lasted three and a half years, almost four, and it started going out.

Identification of when situation was altered:
- -When I turned 13 I started having more trouble.
- -Then it just went like that until about 37 days ago and that's when I came in for the BMT.

Time perceptions significant to progress of situation:
- -It's been a year and a half (since diagnosis).
- -So, I go to dialysis about two weeks afterward.

Effective coping perceived as developing over time:
- -It's still scarey. I think it always will be. But eventually you get a little better and better.

Evaluation of the Situation Themes

The participants were involved in an evaluation of the situation which had several sub-themes described in Table 7 with examples of significant statements. The theme cluster, evaluation process of the situation, included (a) the inability to identify satisfactory alternatives to the choices offered, (b) inability to identify alternative coping strategies, (c) evaluation of the chances of improvement or survival based on scientific advances, (d) comparison of own situation with that of others, (e) evaluation of the effects of different possible outcomes on self or others, (d) decision making related to identification of a goal, and (e) perception of ability to tolerate situation changes.

Coping Themes

Coping with the situation emerged as a major theme category. Coping was done through thought processes, actions, attempts to clarify the situation, attempts to deal directly with the situation, acceptance/tolerance of the situation, patience, and resolve. Thought themes for coping included both content and process. Content focused on (a) positive aspects of the current situation, (b) unrelated or pleasant past events,

(c) visions of pleasant outcome, (d) aspects of the situation which were non-life-threatening, and, (e) technical aspects of the situation. Table 8 provides a summary of thought process themes and examples of significant statements.

Avoidance was a major coping theme which was evident in both thoughts and actions. (see Table 9) Participants described inner, conscious dialogues with themselves to avoid unpleasant or disturbing thoughts about the situation. Such avoidance attempts were not consistently effective. Actions which were done for avoidance included involvement in distracting, enjoyable, and/or fun activities; sleep or rest; and, involvement in interactions with family, friends and/or health care personnel.

A third major coping theme cluster involved coping directly with the situation (Table 10). Themes which emerged included: attempts to live as well as possible; learning to perform medical self-care; active involvement in self care; and, identification of alternative goals and priorities. Three attitude themes emerged when participants described coping directly with the situation. They were acceptance, patience, and resolve.

A fourth coping theme cluster which emerged was clarification of the situation (Table 11). Participants seemed to attempt to clarify the situation for more than evaluation purposes; the process of clarification seemed to be a means of coping. Participants clarified the situation by learning more about the situation through reading and through obtaining technical information and/or instructions from health care personnel. Clarification also occurred through discussion of the situation with others--mothers and significant health care personnel primarily, but also parents generally and pastors.

The theme cluster, factors effecting coping, (Table 12) included faith, the presence or absence of others, the amount of physical discomfort, mastery of previous difficult experiences, and time. Faith factors are a sense of God's presence and control of the situation and the prayers of others. Time factors which effect coping include having a respite between procedures, level of maturity, and whether events are expected or not when they occur.

Table 7

Theme Cluster 2A: Evaluation Process of the Situation

Inability to identify satisfactory alternatives to choices:
- -So I had to take the treatments.
- -I thought, "I don't want to do this, I wish I didn't have to do this."
- -Going, it just seemed like you were walking into being sick.

Inability to identify alternative coping strategies:
- -That's the only way I could stay strong about it and not really get down and stuff.
- -You still think, "Oh, gosh, I have to take care of this, but I've got to do it so I won't be going around smelling."

Evaluation of the chances of improvement based on scientific progress in treatment:
- -And they had 6-MP, methotrexate, vincristine, and adrian. And that's all she had and she survived.
- -My kidney doctor told me "By the time you go through this again we'll have this perfected."

Evaluation based on comparison of own situation with that of others:
- -She left the hospital in seven days after her operation. I thought there's no way that's going to happen to me.
- -You can think about people that are worse, in worse shape. So I look at that. If I think of somebody being burned or something I think, "I feel better than that".

Evaluation of the effects of different possible outcomes on self and/or others:
- -You start thinking a lot. Wondering how it would affect everybody; how it would affect your parents if you were to die.
- -If I thought I was going to have it (colostomy) forever, I don't think I would have (had surgery).

(table continues)

Table 7 (continued)

Decision making related to goal identification:
- -I just think if it's something that will make me feel better then I'll do it.
- -Have a goal and try to beat it--especially after I learned about this one guy that was 33 when I was in here about a year ago and he was really doing good.

Perception of ability to tolerate the situation changes when the situation itself changes:
- -Suddenly they found me in my hiding place. I had no place to go.
- -And then when I start doing OK I'll skip maybe two or three months and then I'll have to go back and start talking to her (counselor) once a week again.

Table 8

Theme Cluster 3A: Coping Through Thought Processes

Attention focus on positive aspects of situation:
- -I don't know if they really mean it, but Mom, she comes in and tells me I look better every day.
- -She tells me (friend who died) is in a better place and everything. Which is probably true.
- -So you just think about all the good points and don't even look at all the bad and it's a lot easier.

Attention focus on unrelated and/or pleasant past events:
- -(When) there's something you think and you say, "Oh, no, we can't think about that." You just have to think of something else. And you're sitting there, "Remember when..." And in your mind you're saying all this stuff to yourself and thinking about this other stuff. It helps you a little.
- -My friends come up quite often on the weekends. Just sit and talk to them for a while. That's pretty helpful. They tell me what's happening in (hometown). I miss it.

Attention focus on pleasant or future outcome:
- -That, (avoidance thoughts) and, you know, just looking forward.
- -After they did it and I woke up and they'd say something every now and then. But I would just fall back asleep. And I would hear them talk a little more. I knew I was alright then.
- -Just thinking it's going to be over. Try not to look at the bad things.

Attention focus on non-life-threatening aspects:
- -I go "Well, I don't want to take the treatments. I'd just rather keep my hair."
- -At the time when she told me about that boy, I wasn't really aware and I didn't really understand the severity of cystic fibrosis. I didn't realize that it (cystic fibrosis) was such a serious disease.

(table continues)

Table 8 (continued)

Attention focus on technical aspects of treatments and/or procedures:

-One thing kind of distracted me and made it easy for me was my interest in high technology things and it was just so amazing.

-It was neat, just sitting there watching them do that. Got to watch them on the television screen. Watching was enjoyable.

Table 9

Theme Cluster 3B: Coping Through Avoidance

Attempts to avoid unpleasant or disturbing thoughts:
- -Do things to keep your mind off it and keep active.
- -I'd just act cheery all the time and I'd just try not to think about it.

Avoidance not always effective:
- -I just tried not to think about it until somebody brought it up.
- -After you've accepted it you just don't think about it until somebody wants to talk to you about it or something like that.
- -Here I was (on operating table) and I realized that I was being real naive about the whole thing before, not thinking about it and stuff before...I realized I shouldn't have done that.

Conducts inner dialogue or exerts effort to consciously avoid thoughts about disease and procedures:
- -Most of the time I just try not to think about it.
- -I just talked myself out of it. Put my mind on something else and the scaredness went away.

Avoidance through involvement in distracting, enjoyable and/or fun activities:
- -I tried not to think about it. I'd do things I like to do...we went to the zoo and stuff like that.
- -So, the last week comes and I'm trying to cram all this fun into the last four days and I just do that so I don't have to think about it.

Avoidance through sleep or rest:
- -But, and then sometimes I'll just go to sleep.
- -Just laying in the bed, what I do mostly.

Avoidance through interaction with family, friends, or HCP:
- -I did a lot of things. I went down and played pool a lot. Talked to people. There were a lot of visitors.
- -I tried not to think about it. I stayed up and ran around the hospital. I gave the nurses a hard time. They'd say, "Will you go to bed!"

Table 10

Theme Cluster 3C: Coping Directly with the Situation

Attempt to live as well as possible:
- -Just live your life the best you can and try to make the most of it.
- -You just try to be as comfortable as you can.

Learning to perform own medical care:
- -So I tried to learn. I watched real closely, because if I'm going to have to go home and do this by myself, I want to do it right...
- -Learn to take care of yourself the best you know how.

Identification of alternative goals and priorities:
- -So I've had to stay out of school for a while until I can get back on my feet better.
- -If I can't get my mind renewed to where I don't believe that I have cxystic fibrosis, maybe it will take some kind of drug or antibiotic or something until they find a cure.

Attitudes of acceptance, patience, and resolve:
- -I think just being able to accept your disease and learning to live with it and taking good care of yourself.
- -I just couldn't get over it. You just have to get used to it.
- -I guess it just takes a lot of patience.
- -Just feel like, you've got to go through it. You've got to get well.

Table 11

Theme Cluster 3D: Coping Through Clarification of the Situation

Learning about situation:
- -I like to hear (about what was going to happen) and I really just listen to it and think it's just something the doctors do everyday and it's just no big hairy deal. That's the way they acted.
- -After I learned about it I felt it was OK.

Learning through reading:
- -And then, I can read. (Social worker) will give me books to read. I read about other kids that have survived and told their story and everything.
- -And so, I read the little books about these things. I figured well, if they can do it, I can too.

Learning through technical information:
- -I had asked one of the doctors previously if I could get a videotape recording of the surgery. I just wanted to see what was going on.
- -And then after I had to take care of it (colostomy) they'd come in and teach me how to do it.

Clarification through discussions with others:
- -But then me and my mom, we talked it out. Then, after that it was OK and I went through surgery.
- -One of the pastors of my church...came up and prayed with me and talked to me and stuff like that. That kind of calmed me down a little bit more than I was.
- -And (social worker), I talk to (social worker) a lot. Once a week.

Table 12

Theme Cluster 3E: Factors Effecting Coping

Faith:
- -Sense of God's presence: I think the Lord was there the whole time...That was my main strength, my mainstay.
- -Prayer of others: So I start wondering what's going to happen , how it (surgery) is going to effect my life and what are all the possibilities. So, I start thinking the church is all praying for me.

Presence of others:
- -Usually I took a friend with me and they'd wait.
- -At least I had my parents there. That helped me through.

Amount of physical discomfort:
- -And standing at radiation you just felt drained. Just really felt bad.

Mastery of previous difficult experiences:
- -I'm more happy than I was the last time.
- -I think having, going through all of them (procedures) before (makes a difference).

Time factors:
- -Having a respite between procedures: They let me lay down some when I came back. For about an hour they did sometimes. That was helpful.
- -Level of maturity: Being older. You know sitting there trying to make yourself vomit when you're that age--kind of ridiculous.
- -Whether events are expected or not: I guess it was just the timing caught me off guard. At 9:30 at night to get called (about an available kidney).

Reactions to the Situation Themes

Participants described both behavioral and emotional responses to the situation. Behavioral responses were unpleasant and included the inability to sleep, trembling, vomiting, tenseness, and coldness. Participants also experienced an inability to control their behavioral responses. Table 13 provides examples of statements indicating behavioral responses to the situation.

Emotional responses described by the participants were both unpleasant (Table 14) and pleasant (Table 15). A variety of unpleasant emotional responses were experienced. The most frequently mentioned emotional reaction was fear. Fear of procedures and treatments was a major theme which will be discussed under the category, dealing with procedures. Other fears related to the situation were fear of dying and of altered physical ability or appearance. Fear was effected by perceptions of time and by the amount of information the participant possessed. Other emotional responses were loss/grief characterized by anger, shock, sadness and depression. Specific losses were related to the death of a significant other person, or to the loss of a physical organ and/or functioning. Anger was directed

at self or others who were perceived to lack understanding. Shock occurred when first learning of the situation or when first gaining a personal awareness of the seriousness of the situation. Sadness and depression were attributed to long hospitalizations, anticipated physical changes, and lack of control caused by medications. Participants also experienced feelings of powerlessness, helplessness, and lack of control of the situation or of their physical self; embarrassment about their physical appearance; disappointment when a hoped for outcome did not occur; aloneness which was overcome by having visitors; and, annoyance or irritability. The participants experienced mood swings which were related to their medication; and they experienced regret of having to deal with the situation, or of the way in which they dealt with the situation.

A variety of pleasant emotional responses to the situation were also experienced. The participants felt gratitude that the situation was not worse or had improved and for the help provided by others. Mothers were most frequently mentioned as helpful, but siblings, visitors, and health care personnel were also included. Gratitude for the comfort that others provided through their discussions was also a theme.

Other pleasant emotional feelings included relief, happiness, comfort, excitement, and a feeling of being special and unique. Relief was gained through the prayers of self and others and through increased knowledge. Happiness was related to a hoped for outcome that occurred though often unexpected.

Table 13

Theme Cluster 4A: Behavioral Responses

Inability to sleep:
-When I'm not handling things well, ...I usually don't sleep very good at night. I sit awake in the bed and just wonder how much longer this is going to go on and stuff.

Trembling:
-And then I started shaking, my hands started shaking.
-You start shaking every once in a while when you start thinking about it. You get real scared.

Vomiting:
-And then I'd start vomiting because of nerves.

Tenseness:
-It struck me right then. I started getting real tense again. I guess, real fast.

Coldness:
-When the doctor told me that, when she first told me I just felt this coldness throughout my whole body because I was just thinking that I was going to die, too.

Inability to control behavioral responses:
-I couldn't sit still. I kept jumping around on the table.

Table 14

Theme Cluster 4B: Unpleasant Emotional Responses

Fear:
- -I didn't think I was going to make it through it.
- -I was thinking that I could be the one it happened to. It could have paralyzed me or something like that.
- -I was worried about it, especially those days going up to surgery; but, I wasn't really worried about it when they (first) told me I was going to have it.

Loss:
- -My dad died last January. That was hard. Besides my grandpa dying before that, and my mom's best friend, and my aunt.

Anger:
- -Sometimes at school they make fun of me and sometimes I get real mad and upset.
- -I kind of got mad at myself right then. Just for a second, that I didn't prepare myself. I (had) just kind of hid all this time.

Shock:
- -And we go and see this specialized doctor a couple of days later and I find out that there's something wrong with my heart. That's kind of a big shock and it throws me off for a couple of weeks.

Sadness and depression:
- -Prednisone makes you feel real different. It makes you moody, sort of. And sometimes that just makes you feel sad, just being on that, you know.

Powerlessness:
- -It was really kind of a helpless feeling after I was strapped down.
- -Like when I was getting ready to go back out (to surgery), I just kept saying, "I don't want to go through this.

(table continues)

Table 14 (continued)

Helplessness:
-I was going to school for a while and I lived in the dormitory and I didn't have anybody to do physical therapy on me up there and I kept getting sick and had to come to the hospital.

Lack of control of situation:
-At first I thought, "I don't want to do this."

Embarrassment:
-It (thoughtless comment by classmate) was in front of the whole class and that really embarrassed me.

Disappointment:
-I was pretty upset because I thought when they put the kidneys in last time they would last, but it didn't turn out that way.

Aloneness:
-It's just me and my mom and my sister.
-Every hour I'd wake up and the nurse would perhaps be away.

Annoyance, irritability:
-It really seemed annoying, that going (to treatments).
-I get irritated over small things.
-This one kid came up to me and said "Are you bald?" I said, "Yeah, what's it to you, anyway!" and I just walked off. He didn't say anything.

Mood swings:
-I almost got the record (for shortness of hospitalization for renal transplant). But, I get down real easy, being here so long.

Regret:
-Before I had my transplant, when I was on dialysis, I would think that if I didn't get burnt I wouldn't have had these problems. I'd be like everybody else.
-I was being real naive about the whole thing before, not thinking about it before (surgery). I realized that I shouldn't have done that.

Table 15

Theme Cluster 4C: Pleasant Emotional Responses

Gratitude:

-My sister was talking to me and she said, "Well you better count your blessings cause some people have it a lot worse. So, that was pretty encouraging.

-I know it (transplanted kidney) won't last forever, but I'm just real, I feel real fortunate it's gone this well, this easy.

-She (social worker) helps a lot. And she helps my mom.

-So my mom started doing therapy with my arm. Put me in water and got it straightened out. The doctors were amazed because they thought I'd never use it and she finally got it straightened out. Everyday, twice a day, and got it straightened out.

-They (brothers and sisters) help me too. While I'm in the hospital they stay with me and they come and visit me. I can't do very much, you know, with this kidney transplant. And they find things we can do, like play games and stuff to keep busy.

Relief:

-So, I go in and get ready for the test and I'm just pretty laid back because everybody else is thinking about me. I let everybody else do all the worrying for me.

-After I learned about it I felt it was Ok.

Happiness:

-When I came in (to the hospital) I was glad because they said it (fistula) looked good and that they could go ahead and take it out.

(table continues)

Table 15 (continued)

Excitement:
-Then one night I was talking to my fiance...(I got a call) Dr.(name) said, "Larry we have a kidney down here for you. You can come on down here to the hospital."

Comfort:
-So that (information) kind of makes you feel better.

Being special, unique:
-You know (name) is the psychologist, but (social worker) volunteered to be mine. I think I'm the only kid that she really talks to.
-And everybody was telling me I couldn't do that. But you can! If you have to you can!

Relationships with Others Themes

The primary relationships that the participants experienced were with health care personnel, family, and others who had the same or a similar illness. The nature of those relationships varied by groups and themes emerged seperately for each. Themes also emerged relating to the influence of others, the influence of others with a similar condition and informing others.

Experiences with health care personnel (HCP) was a major theme in the situations described by the participants. (see Table 16) The participants seemed to be knowledgeable about the roles various HCP assumed, but did not distinguish the authority or helpfulness of one type over others. Frequently, HCP were referred to collectively as "they". All the participants communicated a sense of trust in the HCP. Perceptions of HCP were that they were helpful, caring, and competent. They were helpful in several ways: in providing a knowledgeable, authoritative perspective of the situation; in their use of humor; in providing help to family members; and, in providing an increased level of comfort through their discussions. HCP were experienced as caring through their genuineness and openness, acceptance, willingness to talk, and

understanding of the participant's needs. HCPs' communication style was used as a barometer of the situation where adaptation of a casual attitude and the use of humor are described as helpful.

The power of HCP also emerged as a theme. HCP were perceived as "having" to do unpleasant or undesireable things with good motives. Participants spoke of HCP "having" to use physical restraint in some situations. They desired to have HCP approval and to not cause difficulty for HCP. Participants experienced a desire and/or a compulsion to cooperate with HCP and to gain the understanding of them. For two participants, information that was given by HCP was perceived as inaccurate or misleading, but the participants seemed to adopt a charitable attitude to the incidents.

Relationships with family was another major relationship theme. (see Table 17) The presence of family, especially the mother, was significant to the participants. Family influenced the participants' feelings and provided a sense of closeness. Family members were perceived as understanding, caring, helpful, willing to sacrifice, and concerned.

Other people influenced the participants in many ways. (see Table 18) When another had belief or hope in

some occurrance, the participant's own belief increased. Sharing the experience provided a sense of closeness. Demonstrating the ability to master the situation to others was satisfying. A more positive perspective of the distressing situation was provided with discussions with others. Knowing of and meeting others with similar problems or diseases (Table 19) who did well provided a role model of how to deal with the situation; a sense of hope for a positive outcome; a sense of closeness; and, inspiration.

The participants experienced feelings of empathy towards others who suffer, and they questioned whether comparison of their own condition to that of others was a "right" thing to do when they derived comfort from their condition being better.

Informing others of the situation was a relationship theme which included distinctions between family and friends and strangers. (see Table 20) The participants desired to be selective about who knew of their situation. They desired that the family know about developments in the situation. When friends knew of the situation, the participants experienced a feeling of being understood. In dealing with strangers, the participants perceived them as curious or confused about

their unusual physical appearance. The participants made attempts to explain the situation to strangers; however, they experienced self-consciousness, humiliation and embarassment and annoyance when others learned of the situation without their consent.

Table 16

Theme Cluster 5A: Relationships with Health Care Personnel

Helpful:

-She (social worker) helps me a lot. And she helps my Mom. She just talks to you and makes you feel comfortable about it. Talks about all the kids, that are well and that are off chemo and everything.

-The nurses make you feel pretty good...They just kind of feel like they've known you. Just by joking and things.

-When they told me it (closing colostomy) wouldn't be until June, I'm going "It's so long!" They go "It's really not that long. It's just that you think it's long because we told you it would be earlier." And I did. It wasn't that long after I realized I was making it longer than it was.

-When you're in there and they're talking to you, you feel a whole lot better. Just joked around a lot.

-When they did the cath yesterday, I was awake through it all and it wasn't all that scary. You sit there listening and they talk to you. When they talk to you just talk back like nothing's happening. It was like you were just laying there talking! It was neat.

Competent;

-L. helps. She knows about the colostomy. She's the enterostomy nurse.

-I'm sure the doctors know best, so I'll just do what they say.

-He explained the procedures and what they were going to do and what to expect. Then after that I was fine. Dr. (name), I've known him for a long time.

(table continues)

Table 16 (continued)

Caring:

- -They (nurses) make you feel like part of their family or something. That makes you feel pretty good. It seems like they don't hold back.
- -Pretty soon Dr. S. came in and wanted to know how I was feeling and stuff. He's a real touchy man. He'll touch you on the leg or something like that and want to know how you're doing.
- -She (social worker) helps me through a lot of hard times.
- -My first surgery, my mom, she mostly stayed with me cause I was mostly scared because, you know, my first transplant. But she stayed with me and they (HCP) let her come in with me as long as I wanted.

Communication of HCP a barometer:

- -It's always nice to see that the head guy showed up (for surgery) and he's all calm reacting and in a good mood.
- -I like to hear about what's going to happen and I really just listen to it and think it's just something the doctors do every day and it's just no big hairy deal. That's the way they acted. It's kind of another day for them cause they do all this stuff all the time. It's like the 2000th surgery they just finished.

(table continues)

Table 16 (continued)

Power of HCP:

-I don't think she (physician) told me (of another child dying) just to scare me or anything. I think she told me just to inform me of how severe cystic fibrosis was and that if you don't take good care of yourself it can effect you later on when your disease starts bothering you more.

-They'd have to hold me down for spinals and bone marrows and stuff like that.

-I got up on the table and they strapped me in, then it came back to me pretty fast, what I was here for and stuff.

-And she (nurse) made me do it (care for colostomy). She made me show her that I could do it and she said that I did real good so I was happy about that.

-She was trying to teach me. She said I did better than most of the other ones...So, I tried to learn. I watched real closely.

-When they told me that I still had the fistula, I told them I'll keep the fistula and you can have the colostomy. Dr. J said, "Well, S., I don't think that will be wise." I said, "Well, you don't have that colostomy."

-At first they told me that it was only going to be for about three or four weeks,...but it was three or four months.

Table 17

Theme Cluster 5B: Relationships with Family

Presence of family significant:
- -At least I had my parents there. That helped me through it.
- -My family's so scattered out. They think I'm really doing good because I scared them (during previous surgery). Everybody came in because when I first went down (for surgery) they had to shock me back. That scared everybody so they are worried about this one.

Influence own feelings:
- -I don't know if they really mean it, but Mom, she comes in and tells me I look better every day...You don't know whether she's saying it to make you feel good or if she sees it, but it kind of helps.
- -But I think my friends and all the family and my parents have really pulled me through this pretty good. Kept me cheered up.
- -You start thinking, you start thinking a lot. Wondering how it would affect everybody, how it would affect your parents if you were to die.

Provide a sense of closeness:
- -She (mother) has a chronic disease, too, and she knows how it is to be sick and knows how it is to have to take all those medications and treatments.
- -My mom and sister said "Do you really want to do this?" They knew that I didn't really didn't want to go through with it.

Perceived as helpful/caring/concerned:
- -Mother, she was really worried about it.
- -My parents told me that they cared about me.
- -Mom and dad are pretty encouraging.
- -My sister has my baby.

(table continues)

Table 17 (continued)

Willing to sacrifice:
-We started getting real excited because she was going to be able to give me a kidney.

Provide physical care:
-My mother helps, she helps me a lot. I have to do physical therapy and I have to do it three or four times a day. If I didn't have anybody to do it I just wouldn't be able to stay healthy.
-My mom she started doing therapy with my arm. Put me in water and got it straightened out. The doctors were amazed because they thought I'd never use it. And she finally got it straightened out.

Table 18

Theme Cluster 5C: Influence of Others

Beliefs of others increased own belief:
- -I start thinking, the church is all praying for me.
- -You don't know whether she's (mother) saying it to make you feel good or if she sees it, but it kind of helps.

Sharing provides closeness:
- -After my daddy got killed, me and my grandma got pretty close because she's got cancer of the throat.
- -My one friend helps because she understands I guess better than anybody else, because she had to go through it when she had a C-section. So I guess we kind of understand each other better because of it.

Satisfaction of demonstrating mastery of experience:
- -And everybody was telling me I couldn't do that. But you can! If you have to you can. I was sitting there, couldn't believe that I did it, you know?
- -She said I did better (with colostomy) than most of the other ones because they were just like, "I don't care."

Positive perspective gained through discussions:
- -My sister was talking to me and she said, "Well you better count your blessings because some people have it a lot worse. So that was pretty encouraging.
- -They say it's a pretty good chance (of surviving) as long as I take my medicine and everything.
- -So, wondering what's going to happen to me, I went down two weeks ago and talked to a couple of people down at church and they got everything situated-got everything straightened out, so I started feeling a little bit better then.

Table 19

Theme Cluster 5D: Influence of others with same/similar condition

Role model:
-You accept it by seeing other people that have lived older than you and are doing well and feeling well and learning how to take care of themselves so that they can live longer. You have a goal and try to beat. Especially after I learned of this one guy that was 33...he was really doing good.

Sense of hope:
-I met a girl yesterday, and she's been off chemo for like seven years...I met her and she really,--the way she talks and everything, she really gave me a lot of enthusiasm and stuff about getting well.

Closeness:
-And everybody at the camp that's had kidney problems, they understand each other because of it. They understand that I got burned and what I've been going through and that.

Inspiration:
-And she goes, "Well, believe it or not, there are a lot of people who still go horseback riding, swimming and just do anything they want. They have colostomys and they have them permanent." ...I figure if they can do it, I can too.

Feelings of empathy for others who suffer:
-The baby wasn't going through that same surgery (as I was), but he was going through a surgery, too. And his mom wasn't there, even.

Questioning whether comparison of self with others is right:
-You can think about people that are worse, in worse shape. So I look at that, if I think of somebody being burned or something, I think that I feel better than that. I don't know if that's the way to look at it.

Table 20

Theme Cluster 5E: Informing Others

Selective of who is informed of situation:
-But I didn't point to it (scoliosis) and tell everybody about it.
-I let our church know (about surgery) and my parents.

Desire family to know of developments:
-The first thing I did was call my mom.
-My mom was in (another town) so she had no way of knowing.

Increased understanding when friends informed:
-My friend, she always calls it that thing--"When are you going to get that thing off?" She still doesn't understand what it is and why I have to have it.
-Being able to talk about your disease with other people... Just let them know you can lead a normal life.

Strangers perceived as curious/confused:
-Everyone looked at me real funny and they thought "Gosh, she dyed her hair." (when it grew back a different color)
-Every time someone would say, "What are you in the hospital for?"

Attempted to explain situation to strangers:
-I try to explain to them why I was like this, how I got burned and when and all this.
-We moved back to the city and I went to the same school I used to. I guess they forgot about the films and stuff (used to explain leukemia).

Emotional reactions when others learn of situation without consent:
-Self-consciousness: and not stare at me.
-Humiliation, embarassment: It (comment about wearing a wig) was in front of the whole class and that really embarassed me.
-Annoyance, irritation: Some came up to me and this one kid...said, "Are you bald? I said, "Yeah, what's it to you anyway?" I just walked off.

Transcendence Themes

The transcendence theme, hope emerged from the data with two theme clusters, hope for something (Table 21) and sources of hope (Table 22). Within the theme cluster, hope for something, the participants hoped for wellness, for a conclusion to the situation, to go home, and for improvement in the situation such as improved appearance or lifestyle. They also hoped for "normality". Participants derived their hope from many sources including: (a) an intuitive sense of well being, peace of mind; (b) faith in God; (c) statements by significant others regarding positive outcome; (d) knowing of others who have survived; (e) progress in the discovery of more effective treatment methods; (f) meeting others who are coping well; (g) hearing of the positive outcome of others; (h) belief in a better life after death or after completion of a procedure; (i) previous improvement in the condition; and, (j) lack of further problems over a period of time. Participants identified a tentative nature of hope.

Faith was another transcendence theme which was identified. (see Table 23) Participants experiences of faith in God included prayer by themselves and others. They attributed their well-being to God. They also

experienced struggles to obtain faith in God and the amount of faith changed as the situation changed.

Table 21

Theme Cluster 6A: Hope for Something:

Wellness/Improvement in situation:
- -I said if that's going to help me get better then I'll just take it.
- -You can just look at people that have worse times and you think that in the end it's going to be worth it when you get out.
- -Now, hopefully, this one (kidney) will keep on working for the rest of my life.
- -After I met (name), she's doing OK. She got all her hair back. She's real pretty. She lost all her prednisone weight and everything. She's just so...I think I'll do OK.

A Conclusion to the Situation:
- -You know it's just gotta come to an end so you just gotta kind of push to go (to therapy).
- -As long as I knew it wasn't forever, I knew I could handle it.

Going Home:
- -I felt like I'm in here to get well and I'll be out soon. It's just got to be done.
- -I should be getting to go home tomorrow.

Normality:
- -When I had the surgery I was scared at first, but I also thought, "You're getting a new kidney so I'd be able to lead a normal life."

Table 22

Theme Cluster 6B: Sources of Hope

Intuitive sense of well-being:
-I kind of felt the whole time, even before the operation that you can - you can kind of tell if it's your time. I had a real sweetness, I guess in my spirit and it kind of said just take it easy, just stay calm nothing's going to happen to you. So I did. I just kind of listened to it.

Faith in God:
-So I went in not really believing, but I think the Lord was there the whole time, making me take it easy and saying, "Be calm, you're alright." That was really the main strength, my mainstay.
-Going to church helps.

Statements by significant others of a positive outcome:
-Now, hopefully, this one will keep on working for the rest of my life. They say it's a pretty good chance as long as I take my medicine and everything.
-They say it's going to be worth it so, you look forward to then.

Knowing of others who have survived:
-When that doctor told me that (of another person who died from same disease); when she first told me that I just felt this coldness throughout my whole body, because I was just thinking that I was going to die too--just because she told me about that boy. But, after I learned of other different people that lived longer.

Progress in the discovery of treatment methods:
-I've talked to a lot of kids about it and they think that someday there is going to be a cure for cystic fibrosis. I think there will. They're making new headways all the time.
-My kidney doctor told me, "By the time you go through this again we'll have this perfected." It'll be almost like going through the clinic to have it done.

(table continues)

Table 22 (continued)

Meeting others who are coping well:
- -(You accept it) by seeing other people that have lived older than you and are doing well and feeling well and learning how to take care of themselves so that they can live that longer. Especially after I learned of this one guy that was 33 when I was in here about a year ago and he was really doing good.
- -I met her and she really--the way she talks and everything. She really gave me a lot of enthusiasm and stuff about getting well. I think maybe I'll make it.

Hearing of the positive outcome of others:
- -She just talks to you and makes you feel comfortable about it. Talks about all the kids, that are well and that are off chemo and everything.
- -I learned about one boy that was 33. He's the oldest one that I know of right now, and I decided that I was going to be like him and live a long time.

Belief in a better life:
- -After death: She tells me that B. (friend) is in a better place.
- -After completion of procedure: I still thought it (colostomy) was yucky, but I felt satisfied because I knew it was going to help me to get better and that I didn't have to have it forever.

Previous improvement in the condition:
- -When you get off of it (medication), it (side effect) goes away.

Lack of further problems over a period of time:
- -And this one (kidney), I haven't had any problems with it so far. I'm hoping not to have any.
- -I think I'm doing real well right now.

Tentative nature of hope:
- -And this one (kidney), I haven't had any problems with it so far. I'm hoping not to have any.
- -But I survived it (surgery). I didn't think I was at first.

Table 23

Theme Cluster 6C: Faith in God

Prayer by self and others:
- -I just pray a lot to God that I'll get through this one of these days.
- -One of the pastors of my church...came up and prayed with me and talked to me and stuff like that.
- -I start thinking, the church is all praying for me.

Well-being attributed to God:
- -It's hard for me to admit, but I think I owe a lot of it to the Lord...I think the Lord was there the whole time, making me take it easy and saying, "Be calm, you're alright.
- -It must have been that He wasn't ready for me to go. He was telling me to straighten up or something.

Struggle to obtain/maintain faith:
- -I had lost a lot of faith over the fourteen years (with disease) because it seemed like I couldn't get rid of it totally.
- -There's a lot of people that are healed everyday just through faith. I think there is faith healing. If I can't get my mind renewed to where I don't believe I have cystic fibrosis maybe it will take some kind of drug or antibiotic or something.

Procedure Themes

The two theme categories which emerged related to procedures were (a) dealing with procedures and (b) perceptions of surgery. Several of the theme clusters resemble other theme clusters for dealing with the broader situation of courage described by the participant. Procedures and surgeries seemed to be mini-situations of courage within the more broadly defined courageous situation identified by the participants.

Dealing with procedures. Theme clusters which emerged regarding dealing with the procedure included: anticipation of the procedure, fear, pain, medical technology, positive feelings related to procedures, distraction methods, and the evaluation process for procedures. The theme cluster, anticipation of the procedure (Table 24), was characterized by behavioral reactions which were similar to those for the broader situation including tenseness, inability to sleep, vomiting, crying, trembling, inability to remain still, and screaming. Additionally, participants experienced concern, uncertainty and fear while waiting for the procedure to begin and the transfer to the location of the procedure was difficult.

The theme cluster, fear (Table 25), was characterized by time factors, focuses of fear, and reduction of fear efforts. Time factors included more difficulty dealing with first-time procedures and fear and anxiety during the waiting period prior to the procedure. Fear increased as the time for the procedure approached. The focus of fear was on: changes in physical status such as inability to function effectively or death; being along; disease reoccurance; pain; uncertainty of the outcome; and, intrusiveness of the procedure. Fear was reduced by discussions, medication, increased knowledge, sleep, trust in HCP, and belief in the power of prayer.

The theme cluster, medical technology (Table 26) included observation of machines and procedures, medications, and experiencing a barrage of medical procedures. Regarding the observation of machines or procedures: they were distressful; confusing and strange; intriguing; and, they provided a distraction. Medications were experiences as altering mood or level of conscious. They were viewed as unpleasant, but necessary. The participants also seemed to experience the sheer numbers of procedures for assessment, monitoring, and treatment as being significant.

In the theme cluster, pain (Table 27), participants were able to identify the causes of pain. The disease it self was not as painful as the procedure in most instances. Intrusive procedures were identified as painful. Relief of pain occurred through a conscious effort to control it, through distraction, sleep, or medication. Pain was not a predominant factor in dealing with procedures.

Positive reactions to the procedure (Table 28) was a theme cluster which included relief, happiness, comfort, pride, and a sense of being cared for. The participants experienced relief when the procedure was less distressful than anticipated, when the procedure was completed, and when coping strategies were found to be effective. Happiness was experienced with evidence of progress or completion of the procedure. Comfort was experienced from the realization that others experience similar feelings and from the presence of others, especially mother, family, pastor, and visitors. Pride was experienced for accomplishments. A sense of being cared for occurred through prayers, verbal comments, receiving tangible presents, visitors, and physical touching.

Distraction methods for dealing with the procedure were numerous. (see Table 29) They included concentrating on breathing, creating a visual story in thoughts, doing artwork, dealing with one aspect of the procedure at a time, thinking about past procedures where outcomes were positive, and focusing on the decreased number of treatments remaining after one is completed. Other distraction methods were: conducting a dialogue of reassurance with self, humor, involvement in preparation activities, and observing medical technological aspects of the procedure.

The participants seemed to be involved in an ongoing evaluation of each procedure (Table 30) that they experienced. Procedures were viewed as more or less difficult based on the effectiveness of the participants' coping. Evaluation involved distinctions in sensations, identification of rationale for the procedure experience, and identification of reasons for differences in difficulty. The repetitive nature of a procedure effected its evaluation. Fantasies of procedures were perceived as worse than the actual procedure itself. The behavior of others, including the tone of voice and the amount and type of communication was used as a clue to evaluate a procedure. Also, the

amount of fear others communicated was used as a clue to evaluate the procedure.

Evaluation occurred in comparison to the temporary or permanent nature of the outcome; in comparison to changes in physical ability and structure; and, in comparison to other procedures. Evaluation also occurred in comparison to the reactions of others in similar circumstances.

Table 24

Theme Cluster 7A: Anticipation of Procedure

Behavioral reactions:
- -Tenseness: One of the doctors says, "Well, we're going to get an IV ready in your arm." And that brought it back even faster. It struck me right then. I started getting real tense again.
- -Sleeplessness: I couldn't sleep
- -Vomiting: And then, I'd start vomiting because of nerves.
- -Crying: I almost started crying and things like that... I didn't want to go through with it.
- -Trembling: I was hysterical. I just would shake and like that.
- -Inability to remain still: When (physician) started feeling (where to insert needle), I couldn't sit still, I kept jumping around on the table.
- -Screaming: When I first came here, everytime they'd say what they are going to do, I'd just scream.

Concern, uncertainty, fear while waiting for procedure to begin:
- -When you're sitting in here waiting on them to come and get you, that's when you're scared.

Transfer to location of procedure difficult:
- -That was probably the hardest part of the whole thing. Riding down to the operating room on this table, because I was by myself and I had time to think for about a few minutes.
- -And then going (to radiation treatment), it seemed like you were walking into being sick.

Table 25

Theme Cluster 7B: Fear

Time factors:
- -Difficulty with first-time procedures: Well, my first surgery, I didn't know what to expect and when they took me into surgery I was kind of scared and crying.
- -Fear and anxiety during waiting period: I was worried about it, especially those days going up to surgery.
- -Fear increases as time for procedure approaches: You asked me about the bone marrow. I had one Monday when I came it. I wasn't worried until it was time to go into the room.

Focus of fear:
- -Changes in physical status: I couldn't breathe and that scared me just a little. I thought that I probably wouldn't be able to breathe again.
- -Being alone: I was by myself and I had time to think for about a few minutes. By the time I got down there I was really tense.
- -Disease reoccurrance: I'm not really worried about it (leukemia) when I'm on chemo. It's when they take me off the medicine, it'll probably--I think it will come back.
- -Pain: One thing I worry about this time is how many stitches I'm going to have. Last time when they took the stitches out I'm going, "Is it going to hurt?"
- -Uncertainty of outcome: I didn't know what to expect.
- -Intrusiveness of procedure or surgery: It's just the thought of all those needles going in is what scares me.

(table continues)

Table 25 (continued)

Fear reduced by:

- -Discussions: Me and my mom, we talked it out. Then after that it was OK and I went to surgery.
- -Medications: In about fifteen minutes I was already drugged out so I was already real relaxed. I didn't have anything to be worried about because I was so relaxed.
- -Increased knowledge: He (physician) explained the procedures and what they were going to do and what to expect. Then after that I was fine.
- -Sleep: I cried a lot that night before I went to sleep.
- -Trust in HCP: Dr. S., I've known him for a long time (so I calmed down)...I knew he'd take care of everything and I'd be alright. I had trust in him.
- -Belief in the power of prayer: I had a lot of people praying for me and a lot of it helped.

Table 26

Theme Cluster 7C: Medical Technology

Observation of machines and procedures:
- -Was distressful: I went up there (to BMT Unit) and she was hooked up to the machines that were breathing for her and everything. That really, that thought still goes through my mind, the way she was.
- -Was confusing, strange: When I first came in (to BMT unit) they just told me I had to stay in this room. You know, it's kind of small, kind of wierd, kind of funny.
- -Was intriguing: It was neat, just sitting there watching them do that stuff (catheterization). Got to watch them on the screen up there. It was fun.
- -Provides distraction: They hooked me up to all the instruments, the EKG (electrocardiogram) and the blood pressure stuff. That was real interesting to me so that was diverting.

Medications:
- -Altered mood and/or level of consciousness: Prednisone makes you feel real different. It makes you feel moody, sort of.
- -Were unpleasant but necessary: I have this horrible stuff I have to take, it's white. But I've survived it.

Experienced a barrage of medical procedures:
- -To assess the situation: I started taking all these tests and stuff and they did, I don't know what you'd call it, a biopsy or something.
- - To monitor situation: And they started taking blood pressure and it was doing OK. And weighing me. I had all these heart monitors on, IV's and everything.
- - As treatment: I started taking gut meds. They were bad...And then a week from when I came in I started radiation and that weekend, chemotherapy.

Table 27

Theme Cluster 7D: Pain

Causes of pain identified:
- -I was in a lot of pain because they had taped down my foot because I couldn't roll from side to side. I had to lay on my back.
- -My dad had been telling me that it is one of the most painful operations that you can have because it's just going to hurt your leg for a long time.

Disease itself not as painful as procedure:
- -Well, the leukemia, it doesn't hurt. It's just when you go through bone marrows and spinals and getting stuck with IV's is what really hurts.

Intrusive procedures are painful:
- -The only thing I felt was pain. That's the only thing I really felt.
- -(After the surgery) I was in a lot of pain.

Relief from pain through:
- -Conscious effort to control: The second one (surgery) I only had pain medicine two or three days, cause I tried not to take so much and pretty soon there wasn't much pain.
- -Distraction: One of the nurses told me that the new way of doing that is to think of a story. I said, "Ok, I'll try it and see if it works." And it did.
- -Sleep: I'd just go to sleep and I wouldn't have so much pain.
- -Medication: Everyday, after they finished (debridement) and I'd go back to my room, they'd give me something for pain so it didn't hurt so bad. So, after that it didn't hurt as bad.

Table 28

Theme Cluster 7E: Positive Reactions to the Procedure

Relief when procedure less distressful than anticipated:
-I'm glad nobody knows that I have one (colostomy) unless I tell them. So, it's really not that bad as they think at first.
-So then when they said, "We're going to have to start another IV to put your medicine through", I thought about the same, go through the sticks over and over and over. But it was just two or three sticks was all.

Relief when completed:
-I was real glad about getting it over with.
-(After the surgery), I felt kind of physically relieved, really. That's about it.

Relief when coping strategies found effective:
-I tried that (imagery) Monday and it really works. I think that helps a lot.
-It's OK now cause I'm used to it and it's easy to take care of, really.

Happiness with evidence of progress or completion:
-I'm happy I'm getting it taken care of and it's not going to be as bad.
-That kind of makes you feel good that you're doing good. You don't mind as much when you're making progress.

Comfort from realization that others experience similar feelings:
-Dr. S said there wasn't anything to worry about because there were many people like that who were scared.
-I get irritated...That's only to be expected.

(table continues)

Table 28 (continued)

Comfort from others' presence:
- -Mother: Mom just held my hand and talked to me. That made it better.
- -Family: After my surgery my whole family was there.
- -Pastor: When I woke up I saw my parents and the youth minister, J., That kind of surprised me. That's the first thing I remember when I woke up was him sitting down at the end of the bed.
- -Visitors: It just kind of makes you happy when someone comes to see you all the time. And you know a lot of people come to see me.

Pride for accomplishments:
- -Everybody was telling me I couldn't do that. But you can! If you have to you can.
- -When I first had it? Well she (stoma therapist) was trying to teach me. She said I was a fast learner. I did better than most of the other ones.

Being cared for, supported through:
- -Prayers: I got back and I just thought, all those prayers were answered. That kind of made me feel good.
- -Verbal comments: My parents told me that they cared about me.
- -Receiving tangible presents: All these flowers and balloons and stuff I get in here. That's really nice. I never thought flowers and stuff would make a lot of difference to me in the hospital, but it really does.
- -Having visitors: After the surgery, I woke up and my whole family was there.
- -Physical touching: My mom just held my hand and talked to me.

Table 29

Theme Cluster 7F: Distraction Methods for Procedures

Concentrating on breathing:
-(Nurse) was sitting there helping me breathe and everything.

Creating a visual story in thoughts:
-One of the nurses told me the new way to do it is to think about a story. I said, "Ok, I'll try it and see if it works." And it did.

Doing artwork:
-I like to draw and color. I mostly did that to keep my mind off of it.

Dealing with one aspect of procedure at a time:
-Just kind of going day by day.

Thinking about past procedures where outcomes were positive:
-Thinking about all the good times when we just got stuck on one stick instead of on five--think that we'll just do it on one stick this time.

Focusing on the number of treatments remaining after procedure completed:
-I felt really happy (when procedure was over)...Because that's just one less one.

Conducting a dialogue of reassurance with self:
-I thought that I probably wouldn't be able to breathe again. Then I said, "No, no, no, you're going to be Ok."

Humor:
-He (friend) was just cracking jokes all the time.

Involvement in preparation activities:
-So I packed a few things.

Observing medical technological aspects of procedure:
-I asked some questions about the different instruments and stuff they had. That kind of helped a little.

Table 30

Theme Cluster 7G: Evaluation Process for Procedures

Viewed as more or less difficult based on effectiveness of coping:
-When it's all over you think, "That wasn't really bad."--because you had your mind on the story.

Involves distinctions in sensations:
-The bone marrows are not really too much pain. They are really just discomfort.

Involves identification of rationale for experiences:
-I'm going to have one (nasogastric tube). So, I won't be able to eat. It might tear the stitches out.

Includes identification of reasons for differences in level of difficulty:
-In the spinal taps the whole thing is pain, because they hit nerves and stuff like that.

Evaluation effected by the repetitive nature of the procedure:
-At first I didn't (handle going back for debridement well), because it was new...And then after a while I got used to it.

Fantasies perceived as worse than actual procedure:
-They (spinal taps) are not that bad. It's just the thought of what they're going to do.

Behavior of others used as clues to evaluate procedure:
-Tone of voice, amount and type of communications: They (nurses) are real quiet until it's up to the bad part (of a procedure) and they say "Well, A., how did you like swimming yesterday." I mean, that's really...! I go, "What are you doing?!" I won't answer them. She goes "Nothing. Well, how did you like swimming." I know that they're doing something, so that didn't really work for me.
-Amount of fear communicated by others: Mother was really worried about it. I was worried about it...

(table continues)

Table 30 (continued)

Evaluation occurs in comparison to:

- -Temporary of permanent nature of outcome: They told me it was going to be temporary, that I could always get it taken off. That's what made me go ahead and get it--knowing that I wouldn't have to wear it forever like some people do.
- -Changes in physical ability or structure: I'm going, "What is this? (colostomy) That looks terrible." When I first looked I thought, "Oooo, is that what it looks like?!"
- -Other procedures: When the time comes to do it again, I'll know to get it (surgery) over with and not let it just wait around. I'll get up and get going.
- -Reactions of others in similar situations: Most people it takes a couple of days to roll over on their own.

Perceptions of Surgery Themes

For the six participants who underwent surgery, their experiences of surgery were described in detail. Prior to surgery (Table 31) the experience seemed initially unreal and the preparation activities increased participants' perception of the situation as being real. The waiting period prior to surgery was difficult and a time of evaluating possible outcomes. Physical restraint was significant. The pre-op medication and anesthesia induction were experienced as producing a floating sensation and as a time when there was an unsuccessful attempt to maintain understanding and control.

Immediately following surgery (Table 32) participants experienced an inability to recall the experience of surgery. They were fearful that they had awakened during the surgery because of an altered sense of time--the time lapse during surgery was perceived as short. The participants tried to obtain a personal awareness of the surgery experience. While they obtained a cognitive awareness of what happened from others, they were unable to obtain a sense that the experience actually happened to them. Following surgery the participants realized they were alright, that they

had survived, when they heard and saw others and/or when they were able to determine where they were actually located. Post-operatively the participants experienced alternating levels of consciousness and pain. The pain was expected and it was also subordinate to the feelings of relief of having a positive outcome. Pain was perceived as improving with time and, hence, tolerable.

During the recovery period (Table 33) participants experienced a sense of incredulity that the situation was mastered. Their sense of well-being was based upon evidence of progressive: removal of apparatus, healing, ability to perform activities of daily living, and alleviation of pain. There was an impatience to have the recovery be complete and a desire to return home and resume a desired lifestyle.

Table 31

Theme Cluster 8A: Prior to Surgery

Surgery was a new and unreal experience:
-It (going through the surgery) was something else. It's wierd feeling.

Preparation activities increased perceptions of the situation's reality:
-I got up on the table and they strapped me in. Then it came back to me pretty fast, what I was here for.

Waiting period difficult:
-Just the most scarey part was being in the operating room and being in the waiting room. They got you all prepped to go and then not taking you in the operating room. That was the most scarey because you knew what was going to happen.

Waiting period used to evaluate possible outcomes:
-I was thinking this is my last normal day without a scar...and, tomorrow at this time I'll probably be sitting in the ICU. Thinking where I'd be tomorrow at this time and a week from this time and two weeks from this time I'll be out of here.

Physical restraint significant:
-They put me to sleep, but I didn't want to go through with it so I kept squirming around. Finally, they taped me down.

Medications/anesthesia produced floating sensations:
-He gave me a little shot in the IV tube and I was just kind of floating, you know, just kind of flying around the OR there.

Medications/anesthesia induction attempts to maintain understanding and control:
-I got to number 58 then I couldn't pronounce the words, the numbers, and I was saying them out loud and they got really blurred and slurred.

Table 32

Theme Cluster 8B: Immediately Following Surgery

Inability to recall surgery:
-It was really like it never happened to me, really. I went in and breathed this gas and went to sleep and I woke up with this scar. It didn't seem much like anything happened.

Fear of having wakened during surgery:
-The first thing that went through my mind was I just thought, "Uh-oh, I woke up too early. They didn't give me enough gas or something like this.

Time lapse during surgery perceived as short:
-Then I got to 60 and that was all I remembered. The next thing I know, it seemed just like five minutes later.

Altered sense of time:
-When you're asleep you feel like you slept for at least one day, but you really sleep for a long time, two or three days. I can remember waking up thinking it would be Tuesday and it would be Friday or something.

Attempts to obtain personal awareness of surgical experience:
-Everybody asks me what it felt like when they lost me. (had a cardiac arrest) I said, "I don't know, I don't remember." They said a lot of people said they see a light when they leave and come back but I don't remember.

Cognitive awareness of surgery obtained from others:
-They told me later that I lost a lot of blood during the operation. They had to give me about two units. I ran 30 minutes over the time that they expected. But I couldn't have cared less. I never knew anything about it different.

(table continues)

Table 32 (continued)

Sense of well-being from hearing and seeing others:
-I can remember after they did it and I woke up and they'd say something every now and then. But I would just fall back asleep. And I would hear them talk a little more. I knew I was alright then.
-I heard some little tapping over across the room on the wall. I just barely move, I look over and I saw my family sitting there in the windows.

Sense of well-being when aware of place:
-I woke up, I was in ICU.
-Then after surgery they put me in ICU...I saw my mom and the doctors and the nurses there.

Alternating levels of consciousness:
-I went back to sleep as fast as I woke up
-I can remember after they did it and I woke up and they'd say something every now and then. But I would just fall back to sleep.

Pain:
-The next few days in ICU were really uncomfortable because I was really in a lot of pain.
-Pain expected: I was expecting a tremendous amount of pain at any second, but of course that wasn't the truth.
-Pain subordinate to feelings of relief for positive outcome: Afterwards I was sore and hurting a lot, but I felt pretty good, knowing it was all over with.
-Pain perceived as improving with time, hence tolerable: It did hurt, but it got better.

Table 33

Theme Cluster 8C: Surgical Recovery Period

Sense of incredulity that situation mastered:
- -I was sitting there saying, "I went through this?!"
- -I couldn't believe it when everything's worked out real great.

Well-being based upon:
- -Removal of apparatus: I got out my catheter and my IV that was just--they had me totally chained to the bed with those things and that was just terrible. It improved my condition so much better.
- -Healing: After a while I got used to it (debridement procedure) And, it wasn't sticking as bad. It was just coming off...and it didn't bother me so much.
- -Ability to perform activities of daily living: I can get up and walk around in here...
- -Alleviation of pain: Lots of pain. The first week there's a lot of pain then after that it's not anything.

Impatience for recovery to be complete:
- -I really am anxious to get out.
- -Doctors and most people say I'm doing real well, recovering faster than most. I want to get it over with.

Desire to return home and resume desired lifestyle:
- -I miss my car. I have a brand new car... My fiance comes up everyday, but it's not the same. I can't kiss her or anything like that.
- -I was doing it (exercises) ahead of time because I wanted to get up and out.

Resolution Themes

As the participants described their experience of a situation of courage, several resolution themes emerged. (see Table 34) The participants described a sense of mastery, a feeling of accomplishment and competence. They described a feeling of having learned a lot. The experience served as a motivator to help others and to improve or maintain their condition. They expressed feelings of acceptance of the situation. They attributed the outcome to God's presence and control.

Table 34

Theme Cluster 9A: Resolution

Sense of mastery, feeling of accomplishment and competence:
- -Everybody was telling me I couldn't do that. But you can! If you have to you can. If you have to you really can. I was sitting there, couldn't believe that I did it, you know!?
- -I'm not scared about it anymore. I realize I've got to do it again, so I'll know what to do.
- -After you've accepted it you really just don't think about it a lot. It just doesn't go through your mind.
- -Well, it was pretty easy for me and it wouldn't be so hard to go through again. Because I know how I dealt with it this time. It would be a lot easier to deal with.

Feelings of having learned a lot:
- -I've talked to a lot of people and I've learned a lot about it since then.
- -I guess that's why I'm not upset with myself, because I've learned a lot since I got burned.

Experience serves as a motivator to help others and improve or maintain own condition:
- -I plan on going on to college and being a doctor since I know all of it.
- -I was doing it ahead of time because I wanted to get up and out.

Feelings of acceptance of situation:
- -I feel the reason I was courageous is the acceptance in my life.
- -After you've accepted it, you've just got it and there's nothing you can do, so you really don't feel that bad.

Outcome attributed to God's presence and control:
- -I think the Lord was there the whole time
- -It must have been because He wasn't ready for me to go. He was telling me to straighten up or something.
- -I got back and I just thought, "All those prayers were answered."

Exhaustive Description of Courage in Chronically Ill Adolescents

From the theme clusters, an exhaustive description of courage in chronically ill adolescents was derived. That description is presented in the following sections.

Characteristics of the Situation

A lived-experience of courage in chronically ill adolescents is conceived of as a process which is precipitated when an individual is presented with a health-related event or series of events from which an unclearly defined danger is anticipated. The initial awareness of the situation is characterized by a sense of unreality since no prior major physical symptoms of the condition were present. A personal awareness of the reality evolves either unexpectedly and/or slowly as procedures are undergone to verify and evaluate the health condition. Alternatives within the situation are evaluated and plans are made for treatment.

The lived-experience of courage in chronic illness is dynamic and extends over time. The experiences of time are in themselves significant to the progress of the situation. Waiting periods as the situation unfolds

are times of uncertainty and are evaluated as being long or short. The movement towards courage seems to progress and regress as effective ways of handling the experience develop over time. An awareness of the situation as being one of courage occurs in the process of dealing with the everyday events in a manner which is acceptable to the individual and acknowledged by others.

Evaluation of the Situation

At the occurrence of the health-related event and throughout the situation of courage, an evaluation process occurs. Initially, the individual is unable to identify satisfactory alternatives to the choices which are presented in the situation. A "damage-control" evaluation occurs in which chances of improvement and/or survival are based on three factors: scientific progress in treatment, a comparison of the situation with that of others, and the effects of different possible outcomes on self and/or others. The evaluation of one's ability to tolerate the situation is altered as the situation itself changes. Decision-making related to some goal identification is characteristic of courageous experiences, although in some cases the decisions about treatment modes are not left to the adolescent alone.

While decisions are occasionally related to the type of treatment, they are also related to attitudes and coping methods.

Unwanted physical changes are characteristic of the situation. Such changes affect the life-style and interpersonal interactions of the adolescent in that they may be a source of self-consciousness or concern when interacting with others. They may also alter activities of daily living and quality of life. Occasionally the physical changes may be of greater concern to the individual than the actual disease.

Coping with the Situation

A variety of coping mechanisms are developed and used in the lived-experience of courage. One prominent coping mechanism is avoidance of unpleasant or disturbing thoughts about the situation until and unless necessary. Avoidance is characterized by a desire to live life as "normally" as is possible, not allowing the situation to pervade and consume all other life-experiences. Avoidance is accomplished in a variety of ways: through involvement in distracting, enjoyable and/or fun activities; through sleep or rest; through interactions with others such as family,

friends, or health care personnel; or, through conducting an inner dialogue, a conscious effort to avoid thoughts about the disease or procedures. Such avoidance is used as much as possible. It is a coping method of choice, but is not effective when others mention the situation, when a procedure is perceived as imminent, or when it is used exclusively.

The use of avoidance does not negate the fact that the adolescents are also actively involved in the lived-world situation requiring courage. Involvement occurs through thought processes focused on positive aspects of the situation, on unrelated and/or pleasant past events, on pleasant or future outcomes, on technological aspects of treatments and procedures, or on non-life-threatening aspects of the situation. Especially in the initial phases or in response to a new development, coping occurs through active attempts to clarify the nature of the situation and ways of dealing with it. Such clarification involves learning about cognitive and emotional aspects of the experience by obtaining technical information; by reading and hearing about other similar situations; or, by discussing the experience with others.

Attitudes of acceptance, patience, and resolve are adopted as coping strategies to deal directly with the situation. Adolescents experiencing a situation of courage deal directly with it by identifying goals and priorities for their lives and for the situation. Examples of such goals include attempting to live as well as possible, obtaining a cure by undergoing treatment, and assuming responsibility for self-health care.

Several factors effect the choice and nature of coping strategies used. One factor is faith, a sense of God's presence in the situation which is strengthened through prayer. Another factor is the presence of others who are significant to the adolescent. A third factor is the intensity and duration of physical discomfort. A fourth factor is mastery of previous difficult experiences which are similar to the present situation. Time factors which have a bearing on coping include opportunities for respite from the stresses of the situation; the adolescents' perceived level of maturity; and, whether or not the events which occur in the situation are expected.

Responses to the Situation

A variety of behavioral and emotional responses occur in the lived-experience of courage. The responses occur in the context of the broadly defined situation. They also occur in relationship to more circumspect health-related procedures. Examples of behavioral responses to distress of the situation or the procedure include sleeplessness, trembling, tenseness, coldness, vomiting, inability to remain still, and crying.

Unpleasant emotional responses occur as the individuals struggle within the situation. These unpleasant responses are states which are dominant in the initial phases of the situation. They are also ongoing, but with diminished frequency and intensity as the situation evolves. Many of the responses are related to the grief process, including feelings of loss, anger, shock, sadness and depression. There are feelings of powerlessness, helplessness, and lack of control as the individual is immersed in health-related procedures. Feelings of disappointment and regret occur when the processes or outcomes of the situation are not what are hoped for or envisioned. While feelings of aloneness are experienced, a sense of potential for

lonliness, rather than actual lonliness, emerges as the adolescents describe the gratitude and support they feel from the presence of others. The adolescents experience occasional periods of annoyance and irritability in the prolonged situation. They also feel embarassment when attention is drawn to them as a result of their condition.

The unpleasant emotional responses are mediated by pleasant emotional responses which occur throughout the experience. A movement between the two types of emotions occurs. The feeling of gratitude is a common theme which occurs throughout the situation. Gratitude is directed towards significant others and/or to God. The feeling of relief is also a dominant emotional reaction which occurs in relation to specific situational developments such as when there is a positive outcome or when coping strategies are found to be effective.

A third pleasant emotional response which is experienced is comfort. Feelings of comfort are primarily gained in an interpersonal interaction with significant others such as mother, family, pastor, and visitors. Comfort is also gained from the sense of community with others who experience the same or similar

situations. A feeling of happiness is experienced when hoped for, positive outcomes occur.

Relationships with Others

As adolescents live their experience, a major factor in the movement towards awareness of the situation as one of courage is the nature and quality of interpersonal relationships. Of primary importance are the relationships which develop with health care personnel and with family. Health care personnel are experienced as primarily caring, competent, and helpful. They are used as a barometer throughout the situation. For example, when health care personnel communicate a casual or humorous attitude, the adolescent assesses the situation as being under control. A feeling of being cared for and about occurs through the health care personnel's genuineness and openness, acceptance, willingness to talk, and understanding. Examples of ways in which health care personnel are experienced as helpful and competent include providing an authoritative, knowledgeable perspective of the situation, using humor, providing comfort through discussions, and providing help to family members.

The adolescents experiencing the situation of courage perceive health care personnel as being powerful, but in a benevolent way. Although health care personnel are often the bearers of unpleasant news or inflict unpleasant physical procedures on the adolescents, they are perceived as "having" to do so. The adolescents desire to have the approval and understanding of health care personnel and to minimize the difficulty health care personnel experience. They often feel a compulsion to cooperate with the HCP despite the discomfort such cooperation may cause.

The relationship which is experienced with family members is of primary importance to the situation of courage. The actual presence of at least some family is significant not only when dealing with the difficult aspects of the situation, but also when experiencing the joyful aspects of it. The family member who is often most significant is the mother. Family members are perceived as caring, helpful, and concerned. They are also perceived as willing to make sacrifices in their own lives in order to help in such ways as providing physical care. Family exerts a great deal of influence over the adolescent; their perceptions, evaluations, and support are greatly valued. Finally, a sense of

closeness with family is present or develops as the situation continues.

A third relationship which seems to have a great influence on the lived-experience of courage is with others who have the same or a similar condition. When these others are perceived as doing well, they serve as role models of courage. They inspire and and they provide hope. Feelings of closeness and empathy develop between adolescents who are experiencing similar situations.

All of the meaningful relationships described above are a source of influence on the adolescent. A more positive perspective of the situation is often gained through discussions with others, even while the difficulties and uncertainties of the situation are acknowledged. For example, the beliefs of others in the power of prayer or in the probability of a positive outcome increase the adolescent's own beliefs in the same direction. The sharing of the experience with significant others provides a sense of closeness and understanding between them. A sense of satisfaction from demonstrating mastery occurs after events in the situation have been dealt with in a satisfactory manner.

One area of concern in the lived-experience of courage is informing others of the situation. The adolescents are selective in who has knowledge about the situation. Peers and other acquaintances are perceived as curious and confused and attempts are made to provide them with an explanation of what has occurred. When others learn of the situation without their consent, the adolescents experience feelings of self-consciousness, humiliation, embarassment, and/or annoyance and irritation. The adolescents desire family to know of and share in developments in the situation. They experience a greater sense of understanding from friends once the friends know what has occurred and what is being experienced.

Transcendence

Hope is evident throughout the lived-experience and at some level sustains the individuals during even the worse aspects of the situation. A variety of things are hoped for related to specific events, but two primary hopes are for improvement in the situation or wellness and a conclusion to the situation. Another focus of hope is for "normality" as defined by the individual. When hospitalized, the adolescents hope to go home. The

nature of hope is tentative, but it is sustained from many sources. Sources of hope include: faith in God, an intuitive sense of well-being, statements of hope by significant others, meeting or hearing of others who have survived similar situations or who have had positive outcomes, scientific progress in treatments, previous experiences of positive or improved outcomes, and the lack of further problems over an extended period of time. In dealing with death, a source of hope is belief in a better life after death.

Faith in God is a transcendence theme which emerges for many adolescents as they live out their experience of courage. They experience a struggle to obtain and maintain a valued faith. They are sustained through the prayers of themselves and of others and their well-being is attributed to God.

Courageous experiences with procedures

Within the broadly defined situation of courage experienced by chronically ill adolescents are many daily lived-experiences of courage related to the myriad procedures and treatments which are done. The broader experience of courage evolves from the sequences of events and choices for courage which occur daily. Many

of the elements of these "mini lived-experiences" are similar to those of the identified broad situation, but there are some aspects which are different.

In anticipation of procedures, the same behavioral responses are experienced which were experienced for the over-all situation. The concerns, uncertainties, and fears of the procedure are more focused, however.

Fear is a prominent emotion when dealing with procedures. The first time that a procedure is experienced is the most fearful. Fear is especially prominent during the waiting time prior to a procedure. Fear increases as the time for the procedure draws near and is at or near its highest point during transport to the location of the procedure. Fears of procedures are focused on changes in physical status, on being alone, on the reoccurrence of the disease when treatment is stopped, on pain, on the uncertainty of the outcome, and on the intrusive nature of the procedure. Fear is reduced by discussions, by medications, by increased knowledge, by sleep, by trust in HCP, and by belief in the power of prayer.

Many encounters with medical technology occur. Observations of machinery and procedures are often strange and confusing. They may be distressful, or they

may be intriguing and distracting. At times the adolescents experience so many medical procedures that they seem like a barrage. Such barrages occur initially to assess the situation. They also may occur to monitor the situation, such as following surgery. They may occur in relation to specific treatment regimens, such as a bone marrow transplant. Medications are experienced as an unpleasant, but necessary part of the situation.

The pain experienced in relation to the health condition is often less than the pain related to procedures. In the experience of pain the adolescent identifies the causes of pain such as the intrusive nature of procedures. Relief from pain is accomplished through: conscious efforts to control it, distraction techniques, medication and sleep.

In the lived-experience of courage related to procedures, the adolescents experience many positive emotional responses similar to those experienced for the more broadly defined situation of courage. Relief is experienced when a procedure is completed, when it is less distressful than anticipated, or when coping strategies are effective. Happiness is experienced with evidence of progress in a procedure or when a procedure

is completed. Comfort is achieved from the realization that others have had similar feelings and reactions to the situation. Comfort is also achieved from the presence of others; especially mothers, but also other family, pastors, and visitors. A sense of being cared for and supported occurs through: the knowledge that prayers are being said, verbal statements of care, physical touch, having visitors, and receiving tangible gifts such as flowers and balloons. Feelings of pride are experienced for accomplishing the procedure in the desired manner.

The creative nature of courage is evident as the adolescents develop a number of distraction methods to deal with procedures. These methods include concentration on breathing techniques, guided imagery, artwork, and humor. Distraction is also accomplished by observing technological aspects of a procedure, and focusing on preparation activities. Attempts are made to deal with one aspect of the procedure at a time and focus on the fact that when a procedure is completed, it is one less which needs to be endured.

During the lived-experience of courage with a procedure situation an evaluation process related to the procedures occurs. With such an evaluation, procedures

are viewed as more or less difficult based upon the effectiveness of the coping mechanisms which have been developed. Evaluation involves: distinguishing variations in sensations, the identification of the reasons that procedures are necessary, and the reasons why some procedures are more difficult than others. The behavior of others provides clues in the evaluation. The tone of voice, the type and amount of communication and the amount of fear others communicate are clues to the difficulty of a procedure. Evaluation occurs in comparison to : the temporary or permanent nature of the outcome, the possibility of physical changes in structure or ability, and reactions of others in similar situations.

Surgical Procedures

For the adolescents undergoing surgery, the situation is another in which the lived-experience of courage is manifested. Prior to surgery the experience is new and seemingly unreal. Preparation activities increase the perception of the situation as being real, but waiting periods are difficult. They are used to evaluate possible outcomes. Feelings of loss of control of physical and mental faculties occur when physical

restraints are used and during anesthesia induction.

Immediately following surgery the adolescents frequently experience fear that they have awakened during the surgery, since the time lapse for the surgery is perceived as very short. Inability to recall the the surgery results in attempts to obtain a personal awareness of their experience which resulted in major physical changes. Cognitive awareness of what occurred is provided by others. The sense of time is altered during this immediate post-operative period and the adolescents experience alternating levels of consciousness between sleep and drowsy-awake states. There is a gradual awareness of a sense of well-being which evolves as an awareness of location occurs to the individuals and as the adolescents see and hear others--especially significant others.

Pain is experienced. It is expected. It is often insignificant to the adolescent in comparison to the feelings of relief that the procedure has been completed with a satisfactory outcome. Pain is perceived as improving with time, hence tolerable, and methods of dealing with it are devised and used.

During the surgical recovery period the adolescents experience a sense of incredulity that the situation has

been mastered. The progressive removal of medical apparatus, diminishing amounts of pain, increasing ability to perform activities of daily living, and evidence of a healing process indicate to the adolescents that some level of wellness is being achieved. There are feelings of impatience for the recovery to be complete so that the goals of returning home and resuming or assuming a desired lifestyle can occur.

Resolution of Situation Themes

Through the many daily experiences of dealing with aspects of the situation, a sense of mastery, accomplishment and competence occur for the adolescents. They feel that they have learned a lot. The lived-experience of courage serves as a motivator to continue to maintain and improve their condition. It also serves as a motivator to help and inspire others. There are feelings of acceptance, as though without the experience the individual would not be who and what he is. Much of the outcome is also attributed to God's presence and control.

The Essential Structure of Courage

From the exhaustive description the following essential structure of courage has been derived:

Courage in chronically ill adolescents is an interpersonally-assigned attribute which occurs as the result of a gradual process of living through the experience of having a health-related condition in a specific manner. The initial phase of the lived-experience involves a struggle to gain personal awareness of the nature and impact of the health-related situation of courage. Awareness and resolution of the situation as one of courage is obtained through daily encounters with the many mini-situations of courage: the procedures and treatments, the physical changes, and the alterations in interpersonal relations which result from having the health-related condition. As the nature of the situation is revealed, it is viewed as difficult, but not impossible. Coping strategies are identified or developed to deal actively with the situation, but also to avoid dealing exclusively with it. Other aspects of life are actively persued. Behavioral responses to the situation of courage are experienced. A variety of affective responses are also experienced which are both

positive and negative in nature. The situation of courage evolves in a spiraling regressive-progressive manner towards the realization that the lived-experience is, indeed, one of courage.

The progress towards awareness and resolution of the situation as one of courage is aided by the supportive relationships of health care personnel, family, and others who have experienced similar situations. It is also aided by the transcendence themes of hope and faith. Through the many daily experiences of dealing with aspects of the situation of courage, resolution occurs: a sense of mastery, accomplishment and competence develops. There is a feeling of growth having taken place. The adolescent is motivated to continue to maintain and improve the situation and to help and inspire others. A feeling of acceptance occurs, where the individual acknowledges that the lived-experience of courage has contributed to who and what he is.

Validation of Essential Structure

Following data analysis, three participants were contacted by telephone and asked to validate that the

essential structure of courage was the same as they had experienced. The essential structure of courage was read to the three participants with clarification when complicated terminology was used. The reading was stopped frequently to ask specifically whether each element was experienced by the participant. The three concurred that their experiences were the same as described in the essential structure. Examples of comments during the telephone interview included: "That's exactly what I felt."; "Yes, I did do that."; "You have really summed it up well."

Summary of Findings

From analysis of nine protocols of situations of courage experienced by chronically ill adolescents, 889 significant statements were extracted and restated. Meanings were formulated for each significant statement. Nine categories and thirty-one theme clusters were identified. From the theme clusters, an exhaustive description of courage was derived and the essential structure of courage was identified. The essential structure of courage included the following:

1. A health-related event occurs which is perceived as an unreal, unclearly defined danger.

2. The sense of unreality emerges into a gradual personal awareness of the situation as being one of courage.

3. An evaluation process occurs to more clearly define the nature of the situation and to make decisions about how to deal with it.

4. Coping strategies are identified or developed to deal actively with the situation, but also to avoid dealing exclusively with it.

5. The situation of courage is dynamic, progressive-regressive.

6. Awareness of the situation occurs through daily encounters with the many mini-situations of courage.

7. Physical changes occur.

8. Procedures and treatments are endured.

9. Relationships are altered.

10. Behavioral and affective responses occur.

11. The awareness of the situation as one of courage occurs in the interpersonal context of relationships with others.

12. Supportive relationships with health care personnel, family and others with similar conditions aid the progress towards resolution of the situation.

13. Transcendence themes of hope and faith aid in the progress towards awareness and resolution.

14. Resolution occurs when a sense of mastery, accomplishment and competence develops.

15. As a part of resolution, there is motivation to maintain or improve the situation and to help and inspire others.

16. There is an acknowledgement and acceptance that the lived-experience of courage has contributed to the definition of self.

CHAPTER 5

SUMMARY OF THE STUDY

A summary of the study is included in this final chapter. Following the summary is a discussion of the findings and a discussion of the conclusions and implications of the study. Finally, recommendations for further study are identified.

Summary

The problem of this study was stated as: What are the common components of the lived-experience of courage by chronically ill adolescents? The purpose was to identify the common elements of courage as it is experienced in chronically ill adolescents. In identifying the common elements of courage, an essential structure of courage as experienced by chronically ill adolescents was derived. The conceptual orientation was the phenomenological.

The sample for the study was a purposive sample and consisted of 9 chronicaly ill adolescents who were able to identify and discuss a situation of courage which they experienced. An unstructured interview method was

used to obtain the participants' subjective experiences of courage. These descriptions of courage were analyzed using an adaptation of Colaizzi's (1978) procedure. The essential structure of courage in this study included the following characteristics:

1. A health-related event occurs which is perceived as an unreal, unclearly defined danger.

2. The sense of unreality emerges into a gradual personal awareness of the situation as being one of courage.

3. An evaluation process occurs to more clearly define the nature of the situation and to make decisions about how to deal with it.

4. Coping strategies are identified or developed to deal actively, but also to avoid dealing exclusively with the situation of courage.

5. The situation of courage is dynamic and occurs in a spiral regressive-progressive manner.

6. Awareness of the situation as one of courage occurs through daily encounters with the many mini-situations of courage.

7. Physical changes occur.

8. Procedures and treatments are endured.

9. Relationships are altered.

10. Behavioral and affective responses occur.

11. The awareness of the situation as one of courage occurs in the interpersonal context of relationships with others.

12. Supportive relationships with health care personnel, family and others with similar conditions aid the progress towards resolution of the situation.

13. Transcendence themes of hope and faith aid in the progress towards awareness and resolution.

14. Resolution is characterized by a sense of mastery, accomplishment and competence develops.

15. As a part of resolution, there is motivation to maintain or improve the situation and to help and inspire others.

16. There is an acknowledgement and acceptance that the lived-experience of courage has contributed to the definition of self.

17. A sense of God's presence and control is acknowledged.

Discussion of Findings

The discussion of findings examines the primary conceptualizations of courage identified in Chapter 2 in light of the exhaustive description and essential structure of courage identified in this study. In

addition, it examines the components of courage in relation to a stress-coping model.

Heroism and Courage

As courage seems to emerge from the everyday events in the lived-experience of courage for chronically ill adolescents, the popular image of heroes derived from such classic literature as Homer's Oddessy or Hemingway's For Whom the Bell Tolls. seem to have little resemblance. Conversely, the descriptions of courage by the heroes in the magazines which were catalogued and analyzed by Klein (1953) are supported by the findings of this study. Klein identified that in the process of dealing with problems individuals become far superior to what they were before the experience. In the present study, the adolescents emerged from the experience with a sense of having grown, having learned a lot and having increased in competence.

Fear and Courage

Klein's (1953) study of accounts of courage in magazine articles identified that courageous individuals were not free of fear, but they used fear to gain greater determination. Eventually those individuals were able to free themselves from fear. In the present

study, the adolescents did not describe actually gaining freedom from fear. Instead the participants described an increased ability to cope effectively with their fears. Tillich's (1953) assertion that courage is a bridge between fear and action seems to be a more accurate description of the relationship between fear and courage in the present study. Rachman (1978) viewed courage as the mirror image of fear where fear components include subjective experience of apprehension, associated psychophysiological changes and attempts to avoid or escape from certain situations. The relationship of fear and courage in the present study seems different. The adolescents did experience subjective experiences of apprehension and associated psychophysiological changes. However, the experience of fear emerged as only one aspect among many in the lived-experience of courage, not as a mirror image of courage.

Creativity and Courage

Rollo May, in The Courage to Create (1972), viewed courage as creative existence in the face of anxiety: courage is a necessity to being and becoming. May identified four categories of courage: physical, moral,

social and creative. The adolescents in this study manifested all four of May's types of courage, so that one would question whether they actually are distinct categories. The adolescents experienced physical courage in dealing with their health-condition and the procedures and treatments. They experienced moral courage in their identification with the suffering of others. For example, the participants each expressed an understanding and a sense of community with others who have similar conditions. Social courage, the taking of risks in order to gain intimacy, was evident for all of the adolescents, especially as they made decisions about who to inform about their situation. Creative courage was evident as the adolescents developed numerous coping methods for dealing with procedures. Even more significant, however, is the creation of a new "self". When resolution of the situation was reached, the adolescents all acknowledged themselves as having grown and having gained competence.

Will and Courage

Moran (1967), in analyzing courage as it relates to war, stated that courage is a moral quality; a cold choice between two alternatives; will power. He concluded from his studies, that courage is available in limited supply and needs replenishing--that a man is "finished" when courage is depleted. Klein (1953) also connected will power and courage when he observed that courageous persons willed themselves to succeed, despite tremendous odds. Although the adolescents in the study identified times when they willed themselves to do certain activities or think certain thoughts, the lived-experience was not one of only will power. There were many times when the participants had no desire or will to have anything to do with the situation in which they found themselves and no alternatives were available to them. Overstreet's (1943) view of courage as a product of cultivated attitudes, habits, and relationships, rather than as a choice to be made seems to be a more accurate description of the courage revealed through the present study. As the adolescents lived their experience of courage, enduring the procedures and the behavioral and unpleasant emotional responses, they cultivated attitudes of ability. They

developed habits which were effective in avoiding the situation or in dealing with it directly. In addition, relationships developed which were meaningful and important to themselves and to others.

Overstreet asserted that the seeming differences in amounts of courage which individuals possess is due to the fact that some have managed their lives in such a way that the ingredients for courage are present. Overstreet identified nine ingredients for courage. Each ingredient will be addressed as it relates to the present study:

1. Will to organize and simplify. The adolescents did desire to organize their lives; however, it is not clear from the study that they desired to simplify their lives. Certainly they wished to focus it differently at times--towards more "normal" adolescent activities which included peer group activities.

2. Self-respect. The participants did seem to possess self-respect as they approached resolution and awareness that the situation was one of courage. They possessed a sense of competency and mastery. There were, however, times during the situation when the participants did not like themselves very much. Examples of such times were when medications or

procedures altered their appearance, when they felt they were a bother to others, or when they felt that they were not dealing with the situation as they should, such as when they were irritable. Tillich (1952) described courage as an affirmation of self in the face of human anxiety which is the result of despair of possible pain and suffering. The self-respect, sense of growth, competence, and mastery are akin to such an affirmation of self.

3. Knowledge of what is at stake without courage. A knowledge of what was at stake gradually became evident to the participants following the initial sense of unreality. The participants realized that without enduring the situation there was a greater possibility that they would die or that their quality of life would be less than desired.

4. Resourcefulness. The participants demonstrated an incredible amount of resourcefulness in coping with the broader situation and with the mini-situations of courage. Extraordinarily creative ways of carrying on desired life-styles were developed in spite of the suffering and frustration. As an example, one participant devised a "saran wrap patch" to

be used over her central venous line so that she could swim when she was at camp.

5. View towards the future. Each participant had identified some future-oriented goals for themselves which included some level of maintenance or improvement in their health condition. The concept of hope was identified as an essential component of courage for the sample of chronically ill adolescents in this study.

6. Practicing courage. The fact that the adolescents each had a chronic illness insured that they had ample opportunities to practice their courage. They did so with each mini-situation of procedures and treatments. Practicing courage resulted in progressive-regressive movement towards awareness and resolution of the situation.

7. Maintenance of daily standards in activities. The adolescents used avoidance of the situation of courage to maintain a desireable standard of activities. They continued with school and work activities whenever possible and were involved in the peer activities which their health condition permitted.

8. Companionship. Relationships with health care personnel, family, and others with similar conditions were very important to the participants in their

lived-experience of courage. These relationships were experienced as close, caring, and supportive.

9. Religion--a god figure, set of beliefs, or fellowship of like minds. The transcendence theme of faith in God was evident with most of the participants. Although two participants did not mention specifically, faith in a god, they did not deny such belief. All participants discussed the sense of community they received from knowing others who had similar conditions.

The question of a limited supply of courage is raised by Moran's assertion that courage needs replenishing. As the adolescents described their lived-experience of courage, they described the barrage of procedures that they often faced. One participant in particular seemed to possess an urgent need for a respite from what he viewed as overwhelming. As he described his experience in the interview, he seemed, even then, quite exhausted from the many procedures. It may be of significance that he was the only participant to have died before the study was complete.

The Ontological Nature of Courage

The question of whether courage is an inate quality or one which is obtained has been discussed by several

authors. Tillich (1952) and May (1975) both asserted that courage is ontological--courage is required to even get up in the morning. The participants in the study acquired courage through their lived-experience. Courage was an attribute which was interpersonally assigned in the course of a gradual process of awareness and resolution. Such an assignment of courage to a particular situation does not, however, negate the ontological nature of courage. The present study was not designed to identify the existence of or the level of courage possessed by the participants before they experienced the courageous situation described in their protocols. Situationally developed courage is possible, so that one may possess courage in one situation and need to develop it in others. If courage is situationally developed, some level of courage is likely to emerge for everyone.

Time and Consciousness

There were many indications of alterations of consciousness in the study, especially in perceptions of time. The initial sense of unreality emerged into a gradual personal awareness of the situation as being one of courage. During that process, the perceptions of

time were often not congruent with clock time. The adolescents struggled to gain accurate perceptions of experiences such as when they were unconscious during surgery. Those times were perceived as short. Other times were preceived as much longer than the actual clock time. Such findings are congruent with Margaret Newman's (1979) conceptual framework of the nature of health in which health is conceived as the totality of the life process, evolving towards an expansion of consciousness. Newman has postulated that there is an interrelationship between movement, space, and time in the life process of health (consciousness). According to Newman, time and space are in a complementary relationship. Movement is a means whereby space and time become reality. Finally, time is a measure of consciousness and a function of movement.

Humor and Courage

The use of humor was mentioned frequently by the participants in the study. The adolescents utilized humor as a means of distraction and they appreciated its use by health care personnel. Several participants discussed doing "fun" activities". These findings support Mishkinsky's (1977) study of humor as a "courage

mechanism" rather than as a defense mechanism. Barrie's recommendation to "be not merely courageous, but light-hearted and gay" may be very appropriate for the situations of courage in chronically ill adolescents.

Asarian's Essential Structure of Courage

Asarian's study of courage has special relevance for the findings of this study since he used the phenomenological approach. Asarian identified two types of courageous individuals, assertive determined and dignified acceptance. The assertive determined individuals in Asarian's study dealt with primarily one situation, such as a potential prison riot. The individual identified as having dignified acceptance dealt with a terminal illness. In the present study there did not seem to be a distinction between two types of courage. The adolescents seemed assertive determined when dealing with specific procedures and treatments and they developed a dignified acceptance of the broader situation. The lack of a distinct difference between the adolescents in this study as compared with Asarian's individuals whose courage was either assertive determined or dignified acceptance may have been because the adolescents dealt with mini-situations one at a

time, but they were compelled to also deal with an ongoing health-related condition.

In Asarian's study, the essential structure of courage is viewed as "an intended, arduous, behavioral commitment to values despite formidible conflict, fear, and suffering" (Asarian, p.137). The commitment to goals of improvement or maintenance in the health condition was the focus of the adolescents in this study. However, an intended commitment to values beyond that of health was not clear in this study. The less certain commitment to values may be due to the fact that the participants in Asarian's study were all adults with well formed values, whereas, the present study was of adolescents who were in the developmental stage where values are still forming.

Asarian's essential structure also viewed courage as a social phenomenon which is grounded in the perception of a significant other. This element was well supported in the findings of this study. As part of the essential structure, Asarian identified two phases of becoming courageous. In the pre-courageous phase there is an initial tension in a challenge to values followed by; acceptance of the courageous option, adoption of a stance, formulation of a decision and

disclosed but unclear behavior. In the second phase of living out of the courageous decision, there are four sub-phases:

1. Explicit struggle which has progressive-regressive movement, and coping with consequences and counterfinalities of the decision.

2. Gradual clarification which has recognition of value clarification, development of singleness of purpose, and extension of commitment.

3. Affirmation which includes joy of accomplishment and release from pressure or risk.

4. Reflective recognition of stature: Movement of labeling courage as such for the actor: self-esteem, appreciation of one's humanity, and sense of substantiality.

Aspects of both phases which Asarian identified were present in this study, although they were not divided into two specific phases. The adolescents did experience what may be termed an initial tension. The tension was the challenge posed to at least the value of health. Decision-making occurred following the initial barrage of procedures. At that time, the adolescents were still unclear about what would occur, so they could not be clear about how they would behave in the process

of dealing with the situation. As described in Asarian's second phase, the adolescents were involved in a progressive-regressive struggle attempting to cope with the many procedures and other consequences. A gradual awareness of the situation as being one of courage is similar to Asarian's gradual clarification and extension of commitment. Asarian's sub-phases, affirmation and reflective recognition of stature, closely parallel the resolution described in this study. That these phases occur in sequence is not clear from this study, however. Instead, the affirmation and reflective recognition sub-phases seem to occur cyclically with each procedure, resulting in a cumulative resolution and awareness.

Another part of Asarian's essential structure of courage is "being courageous". In being courageous there are four co-present motivational constituents including:

1. Fidelity to values and extending commitment to values.
2. A network of meaning, the intersubjectivity.
3. Awareness that one must avoid being a coward.
4. The intrinsic meaning of the act itself.

The co-present motivational constituents which

Asarian identified were only partially identified in this study. While the adolescents identified at least health values, at times they waivered in their commitment to them. The adolescents described times when they did not feel that taking the medicines was "worth it". They did not seem to extend the commitment to their values. Again, it may be that in the nature of adolescence, where values are just being internalized, this commitment would not be as strong.

As in Asarian's study, meanings for the adolescents were established within the network of significant others including health care personnel, family, friends, and others with similar experiences. The adolescents did not identify a necessity to avoid being a coward as a strong motivational component of being courageous. One participant did indicate that crying and fussing at her age would not be appropriate. There was some indication that the act of being courageous was in itself meaningful for the participants as resolution was approached. It did not, however, seem to be a motivational constituent for being courageous.

Courage within a Stress-Coping Model

Much of the processes that the adolescents in this study described are similar to the stress-coping-adaptation process. A description of the relationship of stress, coping, adaptation and courage may aid in distinguishing a situation of courage from ones which are not situations of courage. Scott, Oberst, and Dropkin (1980) have identified a stress-coping model in which stress is viewed as any situation in which environmental or internal demands are taxed or exceed the resources available to deal with them. Coping is viewed as a continuous goal-directed process initiated and maintained over time and across encounters by means of cognitive appraisal and regulation of physiological and affective responses. Following person-stressor impact, a primary appraisal occurs. That appraisal involves neurocognitive activation utilizing mental structures (memory systems, codes, abstractions and concept formation) and mental operations (tools of symbolic logic, level of consciousness and problem-solving approaches). Lazarus' (1966) conceptualization of the cognitive process during primary appraisal is incorporated into the stress-coping model. Lazarus asserted that the individual's initial

evaluation of the stress situation in terms of his or her well-being produce one of three possible appraisals of the stressor: (a) irrelevant; (b) benign, resulting in positively toned emotions; or, (c) stressful, resulting in negatively toned emotions. If the stimuli are appraised as stressful, further differentiation occurs and includes: (a)harm or loss--injury or damage already done; (b) threat--anticipated trauma has not yet occurred, assuming a hostile and dangerous environment with the self lacking in resources to master it; or (c) challenge--opportunity for growth mastery or gain, assuming the demands are difficult, but not impossible, using existing or acquirable skills. Following the appraisal decision, affective and physiologic responses occur which lead to a behavior display. A reappraisal of the situation occurs to assess if the goal of overcoming stress has been met. If not, the process of decisions, responses and behavior occur again. When the stressor has been overcome, adaptation has occurred. Adaptation is the result of coping efforts to maintain integrity by establishing a balance between the demands of the stressor and the energy to deal with the stressor.

A comparison of the stress-coping model with the findings of this study indicated that the awareness of having a health-related situation may be viewed as a stressor. The evaluation process within the situation of courage may be compared to neurocognitive activation. The challenge decision, rather than the harm or loss or the threat decisions, contains many similarities to the components of courage identified in the present study. The characteristics of the challenge decision seem to distinguish situations of courage from other situations.

The findings of this study indicated that the adolescents did identify the situation as an opportunity for growth, mastery, or gain, assuming that the situation was difficult, but not impossible using existing or acquirable resources. Following the decision, the adolescents experienced affective and physiological responses and a behavior display occurred. Courage may again be distinguished in the reappraisal phase of the stress-coping model. At that point adaptation in a situation of courage results in feelings of mastery, and competence, whereas when a decision to view the stress as a harm or loss or threat may result in a very different appraisal.

Discussion of Findings Regarding Methodology

There were several findings in relation to the methodology used in this study:

1. As restatements were developed, they often seemed unnecessary because the statements by the participants were general enough.

2. Occasionally the formulated meanings even seemed unnecessary, because the adolescents were very articulate in describing the meaning of the experience.

3. It seemed important when formulating meanings and identifying themes to consider the context of each statement, so that it was helpful to utilize a computer program to sort through the data. By doing so, it was possible to scan the statements to formulate meanings and to identify themes within the context of the protocol.

4. The number of participants in the study seemed to be an appropriate number; although as the last two or three protocols were reviewed for themes, there seemed to be very few new ones.

5. Finally, because of the emotionally charged nature of the subject, it was important to work with small amounts of information at a time, over a longer period of time. Otherwise, it was not possible to

experience the situations to the fullest in order to formulate the meanings.

Conclusions and Implications

Based on the findings of the study, the following conclusions and implications regarding courage in chronically adolescents were derived:

1. Courage more closely resembles a gradual development of attitudes and coping methods than it does the literary descriptions of "born heroes". Such development of attitudes and coping mechanisms occurs over time, through practice, in a progressive-regressive manner, so that the question may be raised whether the often heard admonitions to "be brave" are ineffective and possibly harmful.

2. Courage seems to be a bridge between fear and action, rather than a mirror image of fear. The process of encouragement, then, may be an effective means of obtaining meaningful actions which decrease fears. This study provides some clues to ways in which encouragement evolves, but greater depth in understanding the process is necessary.

3. Creativity is closely connected with courage, including the creation of a new self. Such creativity

does not occur in a vacuum, however. Social supports and other resources are required in order for creativity, awareness of the situation as one of courage and resolution to occur. Supports include opportunities for clarification, discussion of possible coping strategies, opportunities to have the presence of and to interact with significant others.

4. Courage in chronically ill adolescents is not only will-power. Many mini-situations of courage occur which enable the individual to gain knowledge and a sense of competency. Again, the progressive-regressive nature of courage implies that there are times when coping mechanisms may not be as effective as desired and the adolescent may decide at times to view the stressors as a loss or harm or threat. Assistance by health care personnel in the evaluation and decision-making process may be helpful.

5. The situation of courage may not occur at the time of initial diagnosis. The findings of this study indicated that the situation of courage occurs when the individual is confronted with a health-related event which is perceived as an unreal, unclearly defined danger. Occasionally the individual may not comprehend the health-related condition as being dangerous until a

later time, especially if the diagnosis is made at a young age.

6. The present study revealed a struggle with time perceptions experienced by the participants. The waiting times were especially difficult. Insufficient data was obtained to draw any conclusions in regard to what would be helpful during this time, but a sensitivity to the adolescents needs during those times is necessary.

7. The adolescents dealing with situations of courage avoid focusing exclusively on the situation. Daily standards in and opportunities for activities need to be maintained, including interactions with peers and achievement activities such as school. Innovative ways of maintaining activities for chronically ill adolescents may need to be developed.

8. The transcendence themes of faith and hope are an integral part of the lived-experience of courage. Opportunities for expressions of those themes aid the adolescents in gaining awareness and resolution of the situation. This study did not identify the ways in which such opportunities are best offered. Further studies of hope and faith may provide insights into the development of these themes in situations of courage.

9. When adolescents are making decisions to approach each mini-situation as a challenge within the stress-coping model there is a possibility that the barrages of procedures may deplete resources to the point where there is little or no energy left. There is a scarcity of knowledge regarding the amount of stress that an individual can sustain, even when the decision is to deal with a situation as one of courage.

10. The importance of knowing and meeting others with similar conditions indicates that provision of opportunities for meeting such individuals would be helpful. The establishment of peer support groups may be one way of increasing such opportunities.

Recommendations for Further Study

Several recommendations for further study have been identified based upon the conclusions and implications of this study:

1. Relationships with others were identified as being important. Further, indepth, study into the nature of those relationships is recommended, including specific studies of the nature of the caring relationship and the meanings of interactions for the

chronically ill adolescent. Of special interest might be the nature of the caring relationship within families. A study into the effectiveness of support groups is also recommended. With regard to the relationships with health care personnel, further studies might be conducted regarding the process of encouragement. Questions for study include: What activities do health care personnel do that are encouraging? How is encouragement experienced by adolescecents? Can the process of encouragement enhance the development of courage situation resolution and awareness?

2. The factor of time was an important one for the adolescents' experiences of courage. It is recommended that further studies be conducted to investigate experiences of time. Since the waiting times are especially meaningful to the development of courage, it is recommended that further studies be done to determine what is most effective in aiding the adolescents to cope with waiting times.

3. Age factors may have a bearing on the emergence of courage. Questions for further study include: What effect does the development of courage in a situation of chronic illness have on adolescents' later development?

Does courage increase with maturity, since courage relates to specific experiences which develop over time? Or, on the other hand, is the development of courage in chronic illness so situational that courage develops as the situations are encountered? Comparison studies of the components of courage in other age groups or within the adolescent age group are recommended. Another question for study is: What are the differences in the components of courage found in older and younger adolescents?

4. The interpersonal nature of courage leads to questions of what are the effects of admonitions to "be brave"? or, what are the effects of consistent encouragement without respite from stressful procedures?

5. Phenomenological studies of several of the pleasant and unpleasant emotional responses are recommended. For example, study questions might focus on the lived-experiences of comfort, gratitude, relief or humor. Also, they might focus on experiences of powerlessness, anger or aloneness.

6. The relationship between coping and courage needs further study. A study regarding factors which effect choices of coping strategies is recommended.

7. Further study of the transcendence themes of

hope and faith as they are experienced in chronic illness would also be useful.

8. The awareness of the a situation as one of courage and the resolution of the situation leads to a sense of mastery and competence and satisfaction. Further studies of the lived-experiences of mastery and competence are recommended.

APPENDIX A

TWU Texas Woman's University
P.O. Box 22479, Denton, Texas 76204 (817) 383-2302, Metro 434-1757, Tex-An 834-2133
THE GRADUATE SCHOOL

October 23, 1984

Ms. Joan Haase
1412 Bell Creek Dr.
Cushing, OK 74023

Dear Ms. Haase:

Thank you for providing the materials necessary for the final approval of your prospectus in the Graduate Office. I am pleased to approve the prospectus, and I look forward to seeing the results of your study.

If I can be of further assistance, please let me know.

Sincerely yours,

Leslie M. Thompson
Provost

ko

cc Dr. Patricia Mahon
Dr. Anne Gudmundsen

TEXAS WOMAN'S UNIVERSITY
Box 22939, TWU Station
RESEARCH AND GRANTS ADMINISTRATION
DENTON, TEXAS 76204

HUMAN SUBJECTS REVIEW COMMITTEE

Name of Investigator: Joan E. Haase Center: Denton

Address: Joan E. Haase Date: May 8, 1984

1412 Bell Creek Drive

Cushing, OK

Dear Ms. Haase,

Your study entitled Courageous Behavior in Chronically Ill Adolescents: A Phenomenalogical Study

has been reviewed by a committee of the Human Subjects Review Committee and it appears to meet our requirements in regard to protection of the individual's rights.

Please be reminded that both the University and the Department of Health, Education, and Welfare regulations typically require that signatures indicating informed consent be obtained from all human subjects in your studies. These are to be filed with the Human Subjects Review Committee. Any exception to this requirement is noted below. Furthermore, according to DHEW regulations, another review by the Committee is required if your project changes.

Any special provisions pertaining to your study are noted below:

_____ Add to informed consent form: No medical service or compensation is provided to subjects by the University as a result of injury from participation in research.

_____ Add to informed consent form: I UNDERSTAND THAT THE RETURN OF MY QUESTIONNAIRE CONSTITUTES MY INFORMED CONSENT TO ACT AS A SUBJECT IN THIS RESEARCH.

_____ The filing of signatures of subjects with the Human Subjects Review Committee is not required.

_____ Other:

__X__ No special provisions apply.

cc: Graduate School
Project Director
Director of School or
Chairman of Department

Sincerely,

Donald E. Walsh

Chairman, Human Subjects Review Committee

8/10/82

APPENDIX B

The
University of Oklahoma
Oklahoma City Campus-Health Sciences Center

INSTITUTIONAL REVIEW BOARD

APPROVED: May 1, 1984

IRB #: 02563

TITLE: Courageous Behavior in Chronically Ill Adolescents: A Phenomenological Study

Joan Haase
Dept of Nursing
Nursing College Room 449

Dear Ms. Haase,

The Institutional Review Board reviewed the above-captioned applications which will involve human subjects and approved the study. It is the opinion of this Board that the rights and welfare of the individuals who are to be studied will be completely respected; that informed consent will be obtained in a manner consistent with the Code of Federal Regulations, Title 45, Part 46, "Protection of Human Subjects" of March 8, 1983, as amended, and that the risks to the individuals are so outweighed by the benefits to the subject and the importance of the knowledge to be gained that it warrants the decision to allow the subjects to accept these risks.

The Institutional Review Board would like to call your attention to the following obligations as Principal Investigator of this study. Under the terms of our approved Institutional Assurance to the Department of Health and Human Services, you must provide us with a progress report at the termination of the study, or at the annual anniversary date of this approval, whichever comes first. If the study will be continued beyond the initial year, an annual review by the Institutional Review Board is required, with a progress report constituting an important part of the review. The Office of Research Administration will notify you of the anniversary report.

Any substantive changes in the protocol, such as a change in the principal investigator, procedure or number of subjects, should be reported immediately to the Institutional Review Board. These conditions are spelled out in detail in the University of Oklahoma Health Sciences Center Institutional Assurance, dated May 9, 1984, under Section II, A.5. (Supplements); Section II, A.14. (Changes in the research); and Section II, D.6. (Continuing review).

Finally, we urge you to review your professional liability insurance to make sure your coverage includes the activities in this study.

Sincerely,

Fletcher B. Taylor, Jr., M.D.
Chairman, Institutional Review Board

FBT:dlk

STATE OF OKLAHOMA TEACHING HOSPITALS
Post Office Box 26307
Oklahoma City, Oklahoma 73126

Joan Haase, R.N.
Assistant Professor
University of Oklahoma College of Nursing

Dear Joan:

Our office has received written notification of Institutional Review Board approval for your proposal. You may now initiate your study/research activities within the State of Oklahoma Teaching Hospitals in accordance with the information contained in the form entitled "Permission to Implement Research Proposal" previously forwarded to you.

The State of Oklahoma Teaching Hospitals Nursing Research Forum encourages and promotes practice-based research for the purpose of generating new knowledge and validating existing knowledge essential to professional nursing practice.

As Chairperson of the Nursing Research Forum, I welcome your participation with us in this endeavor and look forward to learning of your findings. If I can be of assistance, during your research affiliation with us, please contact me at 271-3990.

Sincerely,

Debbie Brower, R.N. (RO)

Debbie Brower, R.N.
Chairperson
Nursing Research Forum
State of Oklahoma Teaching Hospitals

DB:ks

APPENDIX C

THE UNIVERSITY OF OKLAHOMA

HEALTH SCIENCES CENTER

CONSENT FORM

I, _____ voluntarily consent to participate in the study titled:

Courageous Behavior In Chronically Ill Adolescents: A Phenomenological Study

I understand:

1. Purpose: The purpose of this study is to find the common elements of courage as experienced by chronically ill adolescents.

2. Description of Study: I understand that I will be interviewed about a situation of courage I experienced and I will be asked to describe my feelings during the experience. The interview of that description will be audio-tape recorded. I may also be asked to read the results of the study and tell whether and how my experience of courage is the same as or differs from the description of courage arrived at in the study.

3. Benefits: I understand there are are no known direct benefits to me for participating in the study, nor will any payment be made as compensation.

4. Risks: I understand there are no known risks from participation in this study. The information gained through the interviews will not be reported in my name. The tape recordings will be erased at the conclusion of the study. I will self-select the situation which I wish to discuss, so that it should not be one which I am emotionally unable to handle.

5. Subject's Assurance: I understand that no assurances regarding results can be made. By signing this consent form, I have not waived any legal rights, or released this institution from liability for negligence. I understand I can withdraw my permission and withdraw from the study at any time. Should any problems arise during the study, I may contact Dr. Ralph Daniels, Director of Research Administration, Room 115, University Of Oklahoma Health Sciences Center Library Building, Telephone: 405 271-2090.

6. Signatures:

Date: _____ Participant: _____

Date: _____ Investigator: _____

THE UNIVERSITY OF OKLAHOMA

HEALTH SCIENCES CENTER

PARENTAL CONSENT FORM

I, _____ voluntarily consent for my child to participate in the study titled:

Courageous Behavior In Chronically Ill Adolescents: A Phenomenological Study

I understand:

1. Purpose: The purpose of this study is to find the common elements of courage as experienced by chronically ill adolescents.

2. Description of Study: I understand that my child will be interviewed about a situation of courage he/she experienced and will be asked to describe his/her feelings during the experience. The interview of that description will be audio-tape recorded. My child may also be asked to read the results of the study and tell whether and how his or her experience of courage is the same as or differs from the description of courage arrived at in the study.

3. Benefits: I understand there are are no known direct benefits for participating in the study, nor will any payment be made as compensation.

4. Risks: I understand there are no known risks from participation in this study. The information gained through the interviews will not be reported in my child's name. The tape recordings will be erased at the conclusion of the study. My child will self-select the situation to be discussed, so that it should not be a situation he/she is emotionally unable to handle.

5. Subject's Assurance: I understand that no assurances regarding results can be made. By signing this consent form, I have not waived any legal rights, or released this institution from liability for negligence. I understand I can withdraw my permission and withdraw my child from the study at any time. Should any problems arise during the study, I may contact Dr. Ralph Daniels, Director of Research Administration, Room 115, University Of Oklahoma Health Sciences Center Library Building, Telephone: 405 271-2090.

6. Signatures:

Date: _____ Parent or Guardian: _____

Date: _____ Investigator: _____

7. Participant's Assent
Date: _____ Signature: _____

APPENDIX D

INSTRUCTIONS FOR PREPARING FOR INTERVIEW

Thank you for agreeing to participate in the study of courage I am conducting. Before we talk about the situation of courage you choose to describe, I would like you to think about that situation quite a bit. In the interview I will ask you to :

1. Describe the situation in which you were courageous.

> Describe the situation means to tell about this situation as you were telling a story, including as many details as you can remember about how, when, where and what happened as well as who was involved. Tell what makes this situation different from other situations, so that this is one of courage. Try not to analyze or interpret the situation; just tell about it.
>
> in which you were means I am primarily interested in you : how you acted and behaved.
>
> courageous. There is no particular definition of courage for this study. What you choose to call courageous is what I am interested in.

2. Describe your experience as you remember it including your thoughts, feelings, and perceptions as you remember experiencing them.

> Describe your experience means, again, don't try to analyze or interpret your feelings - simply describe them as completely as you can.
>
> your thoughts and feelings and perceptions means use what ever terms you wish to describe the experience. Stay with you - not how you think a person should or could feel when courageous. For example, what emotions were you feeling? How did your body feel before

during and after the experience? What senses were active and how? What thoughts were running through your head?

3. Continue to describe the experience until you feel it is fully described.

We will take as much time as you need to describe the situation. I am most concerned that we get as complete a description of the situation as you can remember.

If you have any further questions about the interview before we get together, please don't hesitate to contact me. I can be reached at the University of Oklahoma College of Nursing; phone 271-2306. If I am not in when you call, the secretary will take a message and I will return your call. I look forward to talking with you about your courageous experience at _____ on _____ .

Thank you for preparing for the interview.

Sincerely,

Joan Haase

APPENDIX E

Characteristics of the situation
- Event or series of events precipitates courage situation
  - C1, T1, A1, M1, L1, B1, E1,2, S1, D1
  - Initial difficulty perceiving situation as real
    - A5, C17, B2,9, E5, D3,7,19,20
  - No major physical symptoms before informed of situation
    - B10, E3, D1,7
  - Experienced fear T1, B13
  - Procedures done to verify, evaluate situation
    - T6, L3, B3, E7,14, S2, D2,2a
    - Deterioration in condition effects decisions L5, B4
  - Alternatives evaluated, plans made for treatment
    - M3, C7,12, A5, L4, S5, D2a
  - Situation evolved
    - Slowly L2, C7
    - Unexpectedly L2, E2-4, S1,3, D2
    - Progressed in severity L4, B11, S1-3
- Physical changes
  - Were more concern than actual disease
    - A2,3, L5,6, E65, S16
  - Were concern when interacting with others who were uninformed of situation
    - A8, M27, C18-20, S30
  - Were unwanted A3, M28, S4,14,
  - Were source of self-cousciousness
    - A9-11, M27, C5, S30,32
    - Attempted to conceal changes A10, C20
  - Effected activities of daily living (ADL), quality of life L6, S33,121
  - Observing physical changes
    - Was repulsive to self S96,103
    - Was object of curiosity to self S97
- Anticipated physical changes
  - Did not occur as rapidly or with as devastating consequences as originally anticipated A7, S32,122

- Time Perceptions
  - Waiting periods
    - Were time of uncertainty L11, E5-6, E26
    - Were evaluated as being long or short
      - L7,41, L148, E13,26, S116,117, D10
  - Hospitalization perceived as long M47, L133
  - Time lapse between events evaluated as long or short
    - L7,41,148, E13,26, S24, D39,
  - Situation and reactions to it dynamic
    - M6, L4-7,79,88, E32, D11,15
    - Able to identify when situation changed
      - B11, L3, D15
  - Time perceptions significant to progress of situation
    - L1, 12-13, S118,119, D10,47, M3
- Experiencing situation
  - Sense of unreality T30, B10, E64, D5-7, 74

Evaluation process of the situation
-Inablility to identify satisfactory alternatives to the choices or coping strategies offered in the situation
A6, T28, 29, M5,L4,75, B5,45,63,70, S16,20,83-84,113, D49,81
-Evaluation of the odds, chances of improving or surviving situation
S82, C25,33 M25, B22
-Based on progress made in treatment methods
A35, L156
-Comparison of own situation with that of others
C6,44-46,72, E53, L143-145, A34, B6,13,35,38,40,
-Evaluation of the effects of different possible outcomes
-On self E35, S83
-On others E51, S147-149
-Perception of ability to tolerate situation as changes as the situation changes
A45, C14, L5,76,88, B11,41, S27, D96
-Decision making - Identification of a goal
S61, D116, B34,36

Coping with the situation
Thought processes
Focus positive aspects of situation
A63,65, S102-122, D68
Focus on non-life threatening aspects A4, B12
Focus on technical aspects of situation L63,92
Focus on fact that others are worrying,praying
E20,29,46
Attempt to avoid unpleasant thoughts of situation
D73, E29,49
Thoughts to avoid not consistently effective
A55, B71, E29,52, S6,37
Effort focus thoughts away from distressing ones
B71, S36,37, D75,117
On vision of a pleasant future outcome
A64, T10, E57, D76,116
On past, unrelated, or pleasant experiences
T9, E39, D79-80
Inner dialogue
Encourage conscious avoidance of thoughts
About disease and procedure
A31,54, T5,9, L72,74
Actions
Involvement in distraction activities S44
Do enjoyable, fun activities
C35, E27,40,48,55,58
Try new techniques suggested by others A126, D99
Sleep, rest S42, D72, A42
Interactions with others
HCP S44
Be with family and friends C36, E55, D68,69
Through clarification of situation
Learn more about situation B16,17,40, E56, S80

Wishing best possible outcome for others A66
Question whether comparison with others is morally right D64, A66
Fear of undesireable outcome (death) for others A69
Reminise about more pleasant times together A68
Experience repeated thoughts about distress of friend dying A6
Experience fear of undesireable outcome for others A69

The influence of others
-When another had belief or hope in some occurrance, own belief in the event increased A3, D69-70, B53, E17,34
-Physical appearance caused concern
-About the reaction of others S30, A8-18
-About the obviousness of changes S32, C18-19
-Feelings of self-consciousness regarding appearance C20, A8-18
-Experienced unpleasant, taunting comments from some A18, M27
-Coping strategies
-Identify charitable reasons for comments A12, M30
-Focus attention on other activities A19
-Ignored comments A18
-Sharing experience with others provides sense of closeness
-A53, L17,160, B28, M67, S63,138
-Knowing of and meeting others with similar problems, disease who are doing well provides
-example, role model of how to deal with situation B52, A39, S104,108
-hope for own positive outcome A33, B20,35, S108
-sense of closeness M58, A66, B50,51 -inspiration A59, L143, B21,35,36,51, S109
-Demonstrating ability to master situation to others is satisfying
-T29, L97, S71
-A more positive persective of a distressing situation is provided by discussion with others
-S65,104,117, D60, A63,90, M25, C22,48, B17,18,28,30, E35,37

Informing others
Selective about who is informed about situation
C20, E17,28, S31,111,144, D14
Family
Desire family to know of changes in situation
S138,143, L17,21
Strangers
Perceived as curious/confused about physical appearance
A11, S38
Tried to explain situation to others M29, A16, E16
Emotional reaction when others learned of situation
Self-conscious C5
Humiliation, embarassment, A14
Annoyance, iritation M27, A20
Friends
Understanding gained when others know essential nature of situ
S139, B29
Not necessary to know all aspects of situation S140
Unhelpfulness and lack of understanding when friends uninformed
A16

Medical/technological
- Observing machines, procedures
  - Was distressful E,68 A61
  - Was confusing, strange D17,18,57, M42
  - Was intriguing
    - T18, L58,62,85,92
  - Provides distraction
    - L58,63,87, T18
- Medications
  - Altered mood and/or level of consciousness
    - A71, T3,4
  - Were unpleasant, but necessary S88, D21,100,103
- Experienced a barrage of medical procedures
  - To assess situation M11,L3, E14, D8
  - To monitor situation M41, L86
  - As treatment
    - M50, A6, L33, B24, S50-53, D21-24,33,40-44,56
- Experienced a barrage of physical symptoms
  - Headache, D114; Rash,D104, Nausea, D29,37,58, Fatigue D34

Transcendence
- Hope
  - Characteristic: Tentative nature of hope
    - M10, S89, D82,83
    - Identify elements,activities necessary to maintain
      - S20,82, B27,46
  - For
    - Normal activity M14
    - Normal appearance A39
    - Improved lifestyle in future M24
    - Going home D81, M47, C70,80
    - Wellness S20, D65, L155, B36
    - Conclusion of situation D77,85, S82
    - Faith healing B53-59
    - Of scientific discovery of cure B30,60, L157
  - Sources
    - Intuitive sense of well being, peace of mind L120
      - Listened to intuition L121
    - Faith in God L126
      - Religion, church B53-55, E54
    - Statement of significant others regarding positive outcome
      - M25, C10, D68-70,84
    - Knowing of others who have survived
      - A33, B20,36, E53
    - Progress in discovery of more effective treatment methods
      - L157, A34, B30-32
    - Meeting and comparing self with others who are coping well
      - A37, B36
    - Hearing of positive outcome of others
      - A50,57,59, B21,50-57
    - Belief in a better life
      - After death A64
      - After completion of procedure S81
    - Previous experience of improvement in condition
      - A74, L157
    - Lack of further problems over a period of time
      - M10, B41

- Search for purpose and meaning for suffering/for outcome
  M57, B14,60, S137, D59
- Faith
  - Struggle to obtain faith B60,L125
  - Amount of faith changes with situation L127, B60
  - Attributes well-being to God L124, S136
  - Prayer M64, L37,38, E34,47

Dealing with procedures

- Evaluation process related to procedures
  - Viewed as more or less difficult based on effectiveness in coping
    S27,74,80,115, D48,49, A117, M55, C39, L132
  - Involves distinctions in sensations
    A28, M51, L102, E22, S39,54,102,103, D16
  - Identification of rationale for experiences
    L67,118, S10,55,98-100, D11,29,35,107,112
  - Occurs in comparison to
    - Temporary or permanent nature of outcome S41,81
    - Changes in physical
      - Ability L111, D9,16
      - Structure S97
    - Other procedures A29, T13, C83, L43, E22, S54, D25
    - The reaction of others in similar circumstnces
      S40,110, M33, C43,72, L135, B35
  - Includes identification of reasons for differences in difficulty
    S40-44, A29, C24,83, L54, B17
  - Repetitive nature of procedure effects evaluation
    S17,54,56, D12,56, A75, T13, M8,55, C11,33,82, L156-159
  - Fantasies of procedure worse than actual procedure
    A111, L59
  - Behavior of others used as clues to evaluate procedure
    A121-123, S6,12, D5, T10, M19, C42, L83,96,112, E10
    - Tone of voice, amount and type of communications
      A122,123, L96,112, S6,112, E10
    - Amount of fear others communicate
      M15, C15,16, L96, E11,22
- Anticipation of dreaded event
  - Ambivalence between wanting to have procedure finished and not
    L89
  - Produced physical reactions A94
    - Feelings of being hot D47
    - Tenseness L29
    - Inability to sleep A92
    - Vomiting A93
    - Crying A89, C29, S26,131
    - Physical shaking A79, M36, L70
    - Screaming A100
    - Inability to remain still A81, C19
  - Experienced uncertainty, concern while waiting
    T19, C19, L11
  - Transfer to location of procedure very difficult
    L43, S8, D20,44,45,49
- Pain evaluated
  - Causes of pain identified C58,59, E22
  - More difficult when younger M51, A89
  - Disease itself not as painful as procedure A22
  - Intrusive procedures related to disease tx are painful

Outcome evaluation
- Learned alot M59, B64
- Experience serves as a motivator
  - To help others M60
  - To improve condition C70
- Feelings of mastery, accomplishment, competence
  - T29, C83,84, B64, E77
- Feelings of acceptance of situation
  - C2, B68,69
- Belief in God's presence and control of situation L128
  - Wonders whether outcome would be different without God L131

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